

DRAFT PROGRAM

30 march 2021



https://eurocarers.org/2021-iycc















Chair: Tamsin Rose



• Eurocarers Young Carers Working Group members + Professor *Elisabeth Hanson*, Linnaeus University, Swedish Family Care Competence Centre, Me-We coordinator & Eurocarers

Property Representative from the Swedish Government (TBC)

Professor Elizabeth (Betsy) Olson, University of North Carolina-Chapel Hill, U.S.A., ME-WE International Advisory and Ethics Board member.

Helena Dalli, EU Commissioner for equality

15.30 Break

☐ Themed seminars (30 presentations)

IDENTIFY

Raising awareness about young carers - among general public, professionals and policy makers

Host/chair: *Mieke Schuurman*, Eurochild, ME-WE International Advisory and Ethics Board member TBC

- 1. Defining and identifying young caregiving in Spain Rita Cavallotti, Universitat Internacional de Catalunya, Spain
- 2. Prevalence and characteristics of children in care situation in Finland Malla Heino, Carers Finland, Finland
- 3. The challenges of prevalence studies and an alternative approach to estimating young carers Ed Janes, Cardiff University, Wales, UK
- 4. The Reality for Young Carers in Japan Mao Saito, Ritsumeikan University, Japan
- 5. Young carers in Finland many small steps to awareness Jonna Skand, Folkhälsans förbund, Finland

SUPPORT

Addressing the specific challenges faced by young carers in transition to adulthood

Host/chair: *Maria Nilsson*, Linnaeus University, Swedish Family Care Competence Centre TBC

- 1. "Shaping Our Future: Young Carers Transition to Adulthood", Luella Goold, The Children's Society, England, UK
- 2. "Developing A Pathway To Support Young Carers In Transition To Adulthood", Andrew Deacon, Sefton Carers Centre, England, UK
- 3. "Creating a supportive hanger for young adult carers", Sigrid Bosteels, Howest University of Applied Sciences, Belgium
- 4. "How to support young carers to reach their potential during their transition to adulthood", Leah Morgan, Young Carers Development Trust, United Kinadom

LISTEN

The voice of young carers in policies, practices and research

Host/chair: **Young Carer**, Eurocarers Young Carers Working Group

- 1. The Voices of Young Carers in Policy, Practice and Research Daniel Phelps, University of Winchester; Careum School of Health: UK
- 2. Working with Italian former young carers. Participatory research: a way to reach hidden carers

Paola Limongelli, University Milano – Bicocca, Italy

- 3. Care work or caring? Young carers' perspectives Sara Gowen. Sheffield Young Carers. UK
- 4. Not Hidden. Not Janored: Young carers' perspectives on co-design and campaigning

Laura Selby, Sheffield Young Carers and our Young Carers Action Group, UK

5. Young carers about their lifes... Biographical perspective of the parentification experience Barbara Chojnacka, University of Szczecin, Poland





Raising awareness about young carers - among general public, professionals and policy makers

Host/chair: *Bruno Alves,* Cuidadores Portugal, Eurocarers Board member TBC

- 1. "The National Alliance for Young Carers in The Netherlands", Gwen van Roekel, Jonge Mantelzorg Professionals, The Netherlands
- 2. Caring as an art? Young Carers, Artwork and Collaboration", Valerie Gant, University of Chester, UK
- 3. "Sleeping With a Mosquito: From Being a Daughter of Two Parents Suffering from Mental ill-Health To Becoming An Active Change Agent To End Stigma", **Stefania Buoni**, Children of mentally ill parents, Italy
- 4. "How being a former young carer is making me a better social worker", Aiden Quinn, Gloucestershire young carers, Former young carer, England, United Kingdom
- 5. Ask young and ask again! **Outi Arvola**, south west finland Finfami association of families of people with mental illness, Finland

Symposium SUPPORT



"Identify young carers and listen and support them in Belgium; State of play", Samana & Jeunes Aidants proches

'Working together towards carer friendly schools in the Brussels and Flanders regions of Belgium' **Jeunes Aidant Proches, Samana & ZoJong**

Symposium SUPPORT

Promoting the mental health and wellbeing of adolescent young carers in Europe – the 'ME-WE' EU funded research project

Host/chair: *Professor Saul Becker,* University of Sussex, ME-WE partner TBC

- 1. Introduction to the ME-WE project
 Elizabeth Hanson, Linnaeus University, Swedish Family Care
 Competence Centre, Professor, ME-WE Principal Investigator,
 Coordinator, Sweden
- 2. Results from the ME-WE Study: A Cross-National Profile of the Mental Health Well-Being of European Adolescent Young Carers **Feylyn Lewis**, University of Sussex, UK
- 3. Promoting Mental Health Among Adolescents Young Carers in Europe: who cares for legislation, policy and support for adolescent young carers

Agnes Leu, Kalaidos University of Applied Sciences, Switzerland & *Henk Herman Nap*, Vilans, The Netherlands

- 4. Blended Learning Networks in the ME-WE project Renske Hoefman, The Netherlands Institute for Social Research, Marjet Karssenberg, Marlot Bolk, Inge Romeijn, young carers, Yvonne de Jong, Vilans, The Netherlands; Elizabeth Hanson, Linnaeus University, Sweden
- 5. Developing a psycho-educational programme to support young carers the MEWE model
 Licia Boccaletti, Anziani e non solo, Italy





Keynote speech

A Chair: Stecy Yghemonos, Eurocarers Executive Director

Madeleine Buchner, Founder and CEO, Little Dreamers
Australia

9.30

☎ Break

09.45

☐ Themed seminars (30 presentations)

IDENTIFY

Reaching out to young carers and, in particular, hidden/forgotten groups

Host/chair: *Young Carer,* Eurocarers Young Carers Working Group

- 1. An Unheard Voice and an Unmet Need: the situation of young carers in low and middle income countries"

 Anil Patil, Carers Worldwide, UK/India/Nepal/Bangladesh
- 2. Practice: Queering Support Spaces Accommodating and Supporting LGBTQIA+ Young Carers", **Ruth Sullivan**, The Carers Centre for Brighton and Hove Young Carers Project, UK
- 3. Cultural variation in the Experience of Young Carers in the USA", **Amy Dexter**, California State University, San Marcos, Unites States of America
- 4. Breaking down the barriers to identifying the youngest young carers", **Andy McGowan**, Caring Together, UK
- 5. Adolescent Young Carers of grandparents: results from the "ME-WE" online survey", **Sara Santini**, INRCA, Italy

SUPPORT

Supporting young carers' mental health

Host/chair: *Ingrid Lindholm*, Linnaeus University, Swedish Family Care Competence Centre TBC

- 1. Well-being of schoolchildren living with a long-term sick family member: the role of tasks at home and social support Simone de Roos, The Netherlands Institute for Social Research, The Netherlands
- 2. Children supporting children: The introduction of bereavement support groups in Danish schools

 Per Bøge, Danish Cancer Society, Denmark
- 3. Promoting the mental health and emotional wellbeing of Young Carers through Skills for Life programmes

 Hannah Craig, Partnership for Children, United Kingdom
- 4. Factors associated with nature and extent of caregiving, outcome of caregiving and quality of life in a sample of children affected by parental illness and young carers

 Ellen Katrine Kallander, Fafo Institute for Labour and Social

Ellen Katrine Kallander, Fafo Institute for Labour and Social Research Welfare and living conditions, Norway

5. What type of resilience matters for young people who care? **Geraldine Boyle**, The Open University, England, UK

LISTEN

The voice of young carers in policies, practices and research

Host/chair: *Sebastian Fischer*, Chief Executive VOCAL, Board member, Coalition of Carers in Scotland, wir pflegen, Eurocarers TBC

- 1. Listen to young carers: Experiences of Co-Design of research and development work with Young Carers", Rebecca Rolfe, The Children's Society, England
- 2. The voice of experts by experience: how participatory research changed the story of three Italian former young carers **Samia Ibrahim Mohamed**, Italy
- 3. Words Matter

Els Jonker, AJN Jeugdartsen Nederland and JMZ Pro, ambassador Young Caring, The Netherlands

4. Young Carers Unable to Maintain the Household Tomoko Shibuya Igarashi and Takuto Hasegawa, Seikei University, Japan





A Growing Global Network: Raising awareness, listening and responding to the needs of Hidden Young Carers across the Commonwealth. Helen Leadbitter. The Children's Society, England, UK

Host: *Anil Patil*, Carers Worldwide A Chair: David Jones, Commonwealth Organisation of Social Work

- 1. Embedding Participation in Practice: How young carers have influenced change in national and local policy and practice in England. A journey of 20 years with young carers voices embedded at every stage. Helen Leadbitter, The Children's Society, England
- 2. Raising awareness of young carers and the challenges and solutions to developing networks in rural and isolated communities in Australia Madeleine Buchner. Little Dreamers Australia
- 3. Engaging young carers in Kenya in raising the profile and awareness of their needs. Developing a schools programme and the East Africa Young Carers Festival Ernest Mwangi, Young Carers in Kenya and East Africa
- 4. Developing a network for young carers in Canada. Raising the profile of young carers among the public and professionals Jenna Nelson and Chelsea-Anne, Young Carers Program Ontario
- 5. Raising Awareness of Young Carers: a non-stigmatizing approach -Telling the stories of Hidden Young Carers through the ground breaking photographic exhibition *Max Alexander*, Editorial photographer

Symposium SUPPORT

A psychoeducational intervention to promote mental health and well-being of young carers: preliminary evidence of effectiveness in Italy

Host/chair: *Henk Nies*, VILANS, Eurocarers Board member Host/chair: *Pauline Johansson*, Linnaeus University, **TBC**

'The ME-WE intervention Giulia Casu, University of Bologna, Italy *Licia Boccaletti*, Anziani e non solo, Italy Alessandra Manattini, Anziani e non solo, Italy

Symposium SUPPORT

Whole family, multi-stakeholder approaches to support young carers

Swedish Family Care Competence Centre TBC

1. "Finnish service model and tools to support young carers and their families"

Kirsi Hokkila, Joensuun seudun omaishoitajat ry/ALISA-project, Finland

2. "The importance of a whole family approach in supporting young

Benjamin Salzmann, Diakonisches Werk Berlin Stadtmitte, Germany

3. "Evaluating targeted support for young carers in the UK and what changes for young carers (Part 1)"

Daniel Phelps, University of Winchester / Kalaidos University of Applied Sciences, Careum School of Health, UK / Switzerland

4. "The Family Model – supporting mentally ill parents and their children. Swedish experiences'

Maria Afzelius, Dep. of social work, Malmö university, Sweden

5. "Children in families with mental illness – who will support them and how?"

Gisela Priebe, Dept. of psychology, Lund university, Sweden





Symposium IDENTIFY

Research and support of young carers in France: where are we?, Aurélie Untas, University of Paris, France

Host: *Feylyn Lewis*, University of Sussex, ME-WE partner TBC Chair: *Dr Aurélie Untas*, University of Paris

1. Are there young carers in France? Results from the ADO-CARE and CAMPUS-CARE studies among high school and college students

Géraldine Dorard, Eléonore Jarrige, Christel Vioulac, Aurélie Untas, University of Paris

2. What is the level of professionals' awareness of young carers in French Schools?

Aurélie Untas, Pauline Justin, Juliette Henry, Charlène Debruyne, Christel Vioulac, Géraldine Dorard, University of Paris

3. What are the practices of professionals in oncology with young carers? A qualitative study

Pauline Justin, Géraldine Dorard, Aurélie Untas, University of Paris

4. Young carers making a film about their experience during a respite care

Amarantha Bourgeois, Françoise Ellien, French National Association for YC (JADE)

SUPPORT Sibling care

Host/chair: *Young Carer,* Eurocarers Young Carers Working Group

- 1. Sibling cards as a tool for supporting siblings **Katri Lehmuskoski**, Inclusion Finland, Finland
- 2. My personal sibling perspective Being a little sister to an older brother with cerebral palsy & epilepsy from birth **Jessica Lerner**, Public speaker, changemaker, adult carer, Sweden
- 3. Psychosocial resources in the lives of caring siblings from their own perspective A photo novella study **Martin Nagl-Cupal**, University of Vienna, Austria
- 4. Siblings as young carers: Predictors of mental health problems in siblings of children with chronic disorders **Trude Fredriksen**, University of Oslo, Norway

LISTEN

The voice of young carers in policies, practices and research

- Host/chair: *Joost Bronselaer,* Flemish Ministry of Health, ME-WE International Advisory and Ethics Board member TBC
- 1. What does the law say what do the children say?

 Miriam Svensson, Department of Health and Caring Sciences,
 Sweden
- 2. Using views of bereaved children to create change in bereavement support policies

Martin Lytje, Danish Cancer Society, Denmark

3. A cross-national and comparative classification of in-country awareness and policy responses to 'young carers', What has changed in 4 years?

Elena Guggiari, Careum School of Health, Switzerland

4. Youngcaring is lifelong,

Els Jonker, AJN Jeugdartsen Nederland en JMZ Pro, ambassador Youngcaring, Netherlands

5. *The Young Carers Festival*, *Helen Leadbitter,* The Children's Society, England, UK







Siblings as young carers are children, Sweden

Host: *Maria Blad*, Linnaeus University, Swedish Family Care Competence Centre TBC

Chair: Rakel Lornér, Bräcke diakoni

Symposium SUPPORT

SIBS - an evidence-based intervention targeting communication and mental health for siblings and parents of children with disabilities", *Torun Marie Vatne*, Frambu resoure centre for rare disorders, Norway

Host: *Ann-Kristin Ölund,* Linnaeus University, Swedish Family Care Competence Centre TBC

Chair: *Torun M. Vatne*, Frambu resoure centre for rare disorders, Norway

1. The development of SIBS – an intervention aiming to strengthen communication between siblings and parents of children with disabilities.

Torun M. Vatne, Clinical psychologist Phd, Frambu resource centre for rare disorders, Norway

- 2. Practical examples videos from SIBS and discussion
- 3. Developing and implementing an e-learning- and a practical course for providers of SIBS

Christoffer Hals, communication adviser, Frambu resource centre for rare disorders, Norway

4. Prevention of mental health problems for siblings and parents of children with neurodevelopment disorders – A randomized controlled trial (SIBS-RCT)

Trude Fredriksen, Clinical Psychologist/PhD-candidate; Innlandet Hospital Trust & University of Oslo, Norway

5. Online intervention for siblings and parents of children with rare disorders – A multiple baseline trial (SIBS-ONLINE)

Krister Fjermestad, Clinical Psychologist/Professor; Frambu resource centre for rare disorders & University of Oslo, Norway

Symposium SUPPORT

Young Carers policy development and support in Germany -Introduction and brief overview of the German development in awareness of and support for young carers, *Benjamin* Salzmann, Competence center for carers Berlin, Germany,

- Host/chair: *Renske Hoefman,* The Netherlands Institute for Social Research, ME-WE partner TBC
- 1. The situation at national level: support for young carers in Germany
- 2. The situation at regional level: support for young carers in Berlin Prof. Dr. Sabine Metzing, Benjamin Salzmann, Susanne Maurer, Anna Kliem, Dr. Christine Stüben







Professor Saul Becker, University of Sussex, Brighton, UK, ME-WE project partner

9.45 Plenary session 💨 🛂 💆

🖣 Tamsin Rose

Eurocarers Young Carers Working Group members from relevant countries (at different levels in the classification of in-country awareness and support for young carers) to have a policy dialogue with policymakers.

- 1. UK (Advanced) Amy Dickinson + policymaker
- 2. Sweden (Intermediate level) Young carer + Representative from Swedish Government (tbc)
- 3. Italy (emerging) **Stefania Buoni** + **Elisabetta Gualmini**, MEP
- 4. The Netherlands (emerging) young carer + policymaker

11.15 **See Break**





Themed seminars



Identify who and how? - Identification, terminology and experience in policy, practice and research in a Norwegian context, Linda Fisher-Hoyrem, BarnsBeste - National competence network for children as next of kin, Norway

Chair of session:

Siri Gjesdahl, Director at BarnsBeste – national competence network for children as next of kin, Linda Fisher-Høyrem, PhD, Special Adviser at BarnsBeste or Agnes Lundström, Nation Board of Health and Welfare TBC.

1. What is "Children next to kin"? Epistemological and contextual choices and potential consequences for these children's everyday lives.

Borgunn Ytterhus, professor, NTNU, Department of public health and nursing

2. Ten years of Norwegian legislation shaped by the terminology "children as next of kin"

Siri Gjesdahl, Director at BarnsBeste – nasjonal competance network for children as next of kin. or *Linda Fisher-Høyrem*, PhD, consultant at BarnsBeste

3. Who are young carers in a sample of children affected by parental illness or Children next to kin? Contextual choices in how we define children's unpaid care for policy development and potential consequences for these children's everyday lives.

Ellen Katrine Kallander, PhD, Fafo Institute for Labour and Social Research, Welfare and living conditions

Programme to be announced

SUPPORT

Supporting young carers' mental health

Host/chair: *Young Carer,* Eurocarers Young Carers Working Group

1. Sleep and Health related quality of life: Pilot study of young carers in the U.S.

Melinda Kavanaugh, University of Wisconsin – Milwaukee, United States

- 2. Young Carers Active Connections: Improving health outcomes for young carers through sport and physical activity *Helen Leadbitter,* The Children's Society, England, United Kingdom
- 3. The Discernment

Monique Jacques, Member of the Eurocarers Young Carers Group, Belgium

4. Mediating and moderating effect of social support in the association between parental illness and well-being among adolescents

Sanne Ellegård Jørgensen, National Institute of Public Health, University of Southern Denmark, Denmark

5. Two sides of the story

Els Jonker, AJN Jeugdartsen Nederland, ambassador Young Caring, The Netherlands





Child impacts when a parent has a mental illness, *Hanna Christiansen*, Philipps University Marburg, Germany

- Host: *Rosita Brolin,* Linnaeus University, Swedish Family Care Competence Centre, ME-WE partner, TBC
- Chair: *Jean Lillian Paul, Hanna Christiansen,* Philipps University Marburg, Germany
- 1. Stigmatization of children of parents with a mental illness Lisa Dobener
- 2. Mental Health Literacy in families with a parent with a mental illness

Markus Stracke

- 3. Parent-Child-Interactions **Julia Fahrer**
- 4. Stop the domino effect for transmission of depression—A randomised controlled trial of a cognitive-behavioural preventive intervention for the children of parents with depression **Johanna Löchner**
- 5. Understanding and developing an early intervention approach and child-focused support in Tyrol, Austria

 Jean Lillian Paul

Symposium SUPPORT

Assessing young carers' needs and providing support tailored to individual needs

- Host/chair: *Sara Santini*, National Institute of Health & Science on Aging (INRCA), Eurocarers Voard member. ME-WE partner TBC
- 1. Measuring the Big Dreams of Little Dreamers Cassandra Lieschke. Little Dreamers. Australia
- 2. Developing the Carers' Alert Thermometer for Young Carers (CAT-YC)

Lynn Kettell, Edge Hill University, UK

3. Evaluating targeted support for young carers in the UK – a quantitative study (Part II)

Daniel Phelps, University of Winchester / Kalaidos University of Applied Sciences, Careum School of Health, UK / Switzerland

4. YCare: Development of a young carer support and skill program

Melinda Kavanaugh, University of Wisconsin-Milwaukee, USA

5. Brighter Futures for Young Carers in Ireland? Measuring outcomes for young carers against the Better Outcomes, Brighter Futures national framework for children using the Health Behaviour in School-Aged Children Study

Nikki Dunne (Family Carers Ireland), *Colette Kelly* (National University of Ireland, Galway), or *Aoife Gavin* (National University of Ireland, Galway)

Symposium SUPPORT

New to Young Carers: Awareness, Research, and Support within the Canadian Context, *Heather Chalmers*, Brock University, Canada

- Host/chair: *Giulia Casu*, University of Bologna, ME-WE partner TBC
- 1. Young Carers in Canada
- 2. Research on Canadian Young Carers
- 3. Supporting Young Carers
- Professor Michelle Lewis, Executive Director, Young Caregivers Association

Dr. Heather Chalmers, Brock University
Yana Berardini-Lakman, PhD Candidate, Brock University
Dr. Andrea Bross Heisensitzer & Cooklete

Dr. Andrea Breen, University of Guelph





9 00

 Valeria Setti, European Commission Coordinator for the Rights of the Child

🖢 Jana Hainsworth, Secretary General of Eurochild

₽ Bruce Adamson, Chairperson European Network of Ombudspersons for Children (tbc)

10.00

Break

Eurocarers

Symposium IDENTIFY

Am I alone in the world?

Pórunn Sigurjónsdóttir, Iceland

Host/Chair: *Young Carer,* Eurocarers Young Carers Working Group

Presentation 1 **Þórunn Sigurjónsdóttir**, Iceland

Presentation 2
Sigríður Gísladóttir, Geðhjálp, former young carer, Iceland

SUPPORT

Technology advancements for and with young carers

Host/Chair: Frans von Zoest, Vilans, ME-WE partner TBC

- 1. *The ME-WE Mobile App workshop presentation*", *Miriam Svensson*, Linnaeus University, Department of Health and Caring Sciences, Sweden
- 2. A co-created website prototype for supporting young carers in Switzerland", **Hannah Wepf**, Careum
- 3. An intervention of Web-based group psychotherapy for adolescents of parents with chronic or/and life threatening disease", *Kr Harrsen*, The Danish National Center for Grief, Denmark
- 4. Using My Experiences of Being a Young Carer to Support Other Young Carers", **Mike Raynor**, Author / Former Young Carer, United Kingdom

Programme to be announced





Overcoming Loneliness

Helen Leadbitter, The Childrens Society, England, UK

Host: *Licia Boccaletti*, Anziani e non solo, ME-WE partner TBC

A Chair: *Daniel Phelps*, Consultant and Young Carers
Researcher

- 1. Who are Hidden Young Carers? Setting the scene, our research and engaging hard to reach young carers

 Helen Leadbitter, Area Manager and National Young Carers
 Lead
- 2. Increasing identification of Hidden / Seldom Heard Young Carers - Learning from 6 'deep dive' regions in England Rebecca Rolfe, Service Manager
- 3. Overcoming Loneliness for Young Carers: Learning from the England-wide Programme. Co-design programme with young carers

Anna Jacklin, Young Carers Participation Worker

- 4. Understanding the barriers to young carers engagement in universal services and activities, increasing confidence, resilience and wellbeing of isolated and hidden young carers. **Esther Grabham**, Young Carers Participation Worker
- 5. Young Carers as Champions for Change, listening to the voices of young carers. **Luella Good,** Service Manager

Symposium SUPPORT



French Symposium,

Association Française des aidants, Jeunes Aidants Proches, Bruxelles & others

SUPPORT

Towards young carers' friendly educational systems

Host/chair: *Agnes Leu,* Kalaidos University of Applied Sciences, ME-WE partner TBC

- 1. Aiming High!: Educational Aspirations of Young Carers" Feylyn Lewis, University of Sussex, United Kingdom
- 2. Supporting young adults carers during their studies: opportunities for higher education institutions. A co-design approach **Benedicte De Koker**, HOGENT University of Applied Sciences and Arts, Belgium
- 3. Possibilities and limits of dealing with young carers' needs in a school counselling system

Anna-Maria Spittel, C.v.O. University Oldenburg, Germany

4. Young Carers in Upper Secondary School and their Future Career Prospects

Breda Moloney, University College Dublin, Ireland

5. Innovative School Education Methodologies and Tools for Guaranteeing Social Inclusion of Young Carers (EDY-CARE project)

Pauline Johansson, Linnaeus University and Swedish Family Care Competence Center, Sweden





Keynote speech

Chair: **Lennart Magnusson**, Linnaeus University, Swedish Family Care Competence Centre, ME-WE project Coordinator

Pamya Subrahmanian, Chief, Child Rights and Protection, UNICEF Innocenti Research Institute (tbc)

12.45

State of the Conference



If you have any questions, please contact Annica Larsson Skoglund e-mail: annica@anhoriga.se tel: + 46 480 418024.

jointly organised by





