DRAFT PROGRAM

13 April 2021

https://eurocarers.org/2021-iycc
### Opening plenary

**Chair:** Tamsin Rose

**Eurocarers Young Carers Working Group members**

+ **Professor Elisabeth Hanson,** Linnaeus University, Swedish Family Care Competence Centre, Me-We coordinator & Eurocarers

**Helena Dalli,** EU Commissioner for equality

**Lena Hallengren,** Swedish Minister for Health and Social Affairs

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

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### 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

1. **Defining and identifying young caregiving in Spain**
   **Rita Cavallotti,** Univeristat 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

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 Kingdom

#### 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; Kalaidos University of Applied Sciences, Careum School of Health; UK/Switzerland

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 Ignored: 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 lives... Biographical perspective of the parentification experience**
   **Barbara Chojnacka,** University of Szczecin, Poland
Symposium IDENTIFY

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

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

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

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 Karsenberg, Marlou 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
09.00  Keynote speech
Chair: Stecy Yghemonos, Eurocarers Executive Director
Madeleine Buchner, Founder and CEO, Little Dreamers Australia

09.30  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

1. Well-being of schoolchildren living with a long-term sick family member: the role of tasks at home and social support Simone de Roo, 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 Research Welfare and living conditions, Norway


**LISTEN**
The voice of young carers in policies, practices and research
Host/chair: Louise Morgan, Director Carers Trust Scotland

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
**Symposium IDENTIFY**


- **Host:** Anita Vatland, CEO Norwegian Alliance for Informal Carers, Eurocarers Board member
- **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

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**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

  ‘The ME-WE intervention

  *Giulia Casu*, University of Bologna, Italy

  *Licia Boccaletti*, Anziani e non solo, Italy

  *Alessandra Manattini*, Anziani e non solo, Italy

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**Symposium SUPPORT**

Whole family, multi-stakeholder approaches to support young carers

- **Host/chair:** Pauline Johansson, Linnaeus University, Swedish Family Care Competence Centre

  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 carers”

     *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


     *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

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**INTERNATIONAL YOUNG CARERS CONFERENCE**

**INTERNATIONAL ONLINE**

**03-06 MAY 2021**

**TUESDAY 4TH MAY**
Themed seminars

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

Host: Claire Cassidy, Carers Trust, ME-WE partner
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

1. What does the law say – what do the children say?
   Miriam Svensson, Rosita Brolin, Linnaeus University, 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
### Symposium IDENTIFY

**Siblings as young carers are children,**

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

*Chair: Rakel Lornér, Bräcke diakoni*

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### Symposium SUPPORT

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

*Host: Mona Pihl, Swedish Family Care Competence Centre*

*Chair: Torun M. Vatne, Frambu resource 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*

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### 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*

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*
9.00  Keynote speech
Chair: Sari Tervonen, Eurocarers President

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

9.30  Break

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 and Ailsa Tweedie + policymaker
2. Sweden (Intermediate level) - Jessica Lerner and Agnes Lundström, Program officer Swedish National Board of Health and Wellfare
3. Italy (emerging) - Stefania Buoni + Elisabetta Gualmini, MEP
4. The Netherlands (emerging) - young carer + policymaker

11.15  Break
Themed seminars

Symposium IDENTIFY

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

Host: Susanne Rolfner Suvanto, Linnaeus University, Swedish Family Care Competence Centre
Chair: 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, National 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 – national competence 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

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
**Symposium IDENTIFY**

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

- Host: *Chiara Lenza*, Linnaeus University, Swedish Family Care Competence Centre
- 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*

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**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 Board member. ME-WE partner

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; Kaledios 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)

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**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

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 Breen*, University of Guelph

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End of DAY 3
9.00  Plenary session
Chair: Kathleen McLoughlin, Vice President Research, Eurocarers
Valeria Setti, European Commission Coordinator for the Rights of the Child
Niall Muldoon, Irish Ombudsman for Children (TBC)

10.00  Break

10.30  Themed seminars

Symposium IDENTIFY
Am I alone in the world?
Þórunn 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 van Zoest, Vilans, ME-WE partner and Nynke de Yong, Vilans, ME-WE partner
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
**Symposium IDENTIFY**

**Overcoming Loneliness**

*Helen Leadbitter*, The Childrens Society, England, UK

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

**Chair:** *Daniel Phelps*, Consultant and Young Carers Researcher; University of Winchester; Kalaidos University of Applied Sciences, Careum School of Health; UK/Switzerland

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, French-Belgian Symposium, Association Française des aidants (Frances) & Jeunes aidants proches Bruxelles (Belgium)**

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

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
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<td>12.15</td>
<td><strong>Keynote speech</strong></td>
<td>Chair: Lennart Magnusson, Linnaeus University, Swedish Family Care Competence Centre, ME-WE project Coordinator</td>
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If you have any questions, please contact Annica Larsson Skoglund
E-mail: annica@anhoriga.se
tel: +46 480 418024.

jointly organised by