



“Every Child has the Right to ...”

2nd International Young Carers Conference

29 – 31 May 2017

Clarion Hotel & Congress Malmö Live, Malmö, Sweden



Nationellt kompetenscentrum anhöriga - The Swedish Family Care Competence Centre (SFCCC)

The SFCCC was established in January 2008, commissioned by the National Board of Health and Welfare via the Ministry of Health and Social Affairs to explore and collect existing research and development work in the area of informal (family) care; disseminate research results and examples of best practice, and support development work and knowledge transfer within municipalities, health care sector, business community and civil society organisations. We act as a link between practice, decision-makers, the voluntary sector and research to support evidence based practice, policy and research in the field of carers, care and caring. The SFCCC is an active member of Eurocarers and the International Association of Caregiver Organisations (IACO).

Linnaeus University

Linnaeus University with 31,000 students is located in Småland. Our high-quality research has had an impact, both nationally and internationally. It covers the humanities, social sciences, natural sciences and engineering, and represents a number of well-established research domains. Examples are labour market policy, welfare issues and entrepreneurship, but also life sciences, aquatic ecology, and timber and energy technology. Carl Linnaeus born in Småland is the Swedish scientist who has had the greatest impact globally. Bold and curious, he made the entire world his arena. Linnaeus University is inspired by the spirit of Carl Linnaeus. Curiosity, creativity, companionship and utility – this is how we interpret the actions of Linnaeus, and this is how we wish to carry out our activities.

BarnsBeste – National Competence Network for Children as Next of Kin (Norway)

BarnsBeste (Children's Best Interests) is established by The Norwegian Ministry of Health for the purpose of supporting children whose family members struggle with addiction, severe illness or injuries. The network collects, systematize and communicates experiences and knowledge about children as next of kin/ young carers. The network consists of researchers and practitioners within health services, social services and education. BarnsBeste aims to support practitioners, local and national authorities as well as NGOs with advice and guidance. BarnsBeste also facilitates the transfer of knowledge across professions, government agencies, treatment levels and educational institutions. By developing guidelines, information and learning-resources, BarnsBeste contributes to enhancing expertise for the benefit of children.

Forte

Forte is a research council funding research on health, working life and welfare. The research Forte funds today paves the way for a more equal and sustainable society in the future. Forte is a government agency under the Swedish Ministry of Health and Social Affairs. Our operations are guided by governmental directives and an annual letter of appropriation. On behalf of the government we initiate and finance research in the areas of health, labour and welfare. We evaluate the effects of research and how the results can be translated into practice, as well as working actively with dissemination of knowledge. Forte creates meeting places where research and the future are the central focus.

The National Board of Health and Welfare (Socialstyrelsen Sweden)

Socialstyrelsen Sweden is a government agency in Sweden under the Ministry of Health and Social Affairs. We produce and develop statistics, regulations and knowledge for the Government, for care providers and professionals. In 2011 we got a governmental assignment to strengthen the support for children as next of kin in health care and social services.

The National Board of Social Services (Socialstyrelsen Denmark)

Socialstyrelsen Denmark is a government agency under The Ministry for Children and Social Affairs. The Board aims at actively contributing to a knowledge based social policy, which furthers effective social initiatives for the benefit of citizens. The goal is to make social knowledge work.

The Norwegian Directorate of Health

The Norwegian Directorate of Health is a technical advisory authority subordinate to the ministry of Health and care services. The Directorate is working continuously to improve public health through determined efforts across sectors, public services and administrative levels. As a specialist, technical and legal advisor the Directorate is continuously monitoring public health and developments within the health and care services. The Directorate is committed to collect up-to-date research and best practices for the purpose of providing standardized guidelines within a wide range of areas. As a competent authority we possess an autonomous advisory role on the basis of technical and legal knowledge. The directorate executes policies on behalf of the Government and the Parliament (Storting). This may involve the implementation of plans of action, bringing about public health campaigns and/or apport goal-oriented grants and subsidies. The directorate has also been delegated the task of interpreting and applying laws and regulations and utilizing numerous reimbursement schemes.

Eurocarers

Eurocarers is the European association working with and for informal carers. We define a ‘carer’ as a person who provides unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside of a professional or formal framework. Our network brings together nearly 60 carers organisations and research institutes from across Europe – a unique combination that enables evidence-based advocacy. Eurocarers works for a future in which caring is recognised and valued, and in which unpaid carers do not face poverty, social exclusion or discrimination. We do this by:

- Raising awareness of the significant contribution made by carers to health and social care systems and the economy as a whole, and of the need to safeguard this contribution; and
- Contributing to policy development at national as well as European level supported by evidence-based research; and
- Promoting mutual learning and an exchange of good practice and innovation throughout the EU.

Since 2009, Eurocarers acts as the secretariat of the Interest group on Carers at the European Parliament, which brings together more than 30 MEPs from 12 member states. In 2014, Eurocarers signed a framework partnership agreement with the European Commission in the framework of the Employment and Social Innovation (EaSI) programme. This allows us to play a leading consultative role in the implementation of the EU 2020 strategy on issues related to the development of adequate, sustainable and equitable long-term care services across the EU.

Region Skåne

Region Skåne is responsible for health care, public transport and sustainable development in the whole of Skåne. We promote the regional economy, the culture and collaborations with other regions in and outside Sweden. Region Skåne’s highest governing body is the regional council, directly elected by the inhabitants of Skåne. With 32,000 employees, Region Skåne is one of Sweden’s biggest employers.

Malmö City

The City of Malmö is a natural hub for people and cultures from worldwide. The city’s inhabitants come from around 170 countries and speak some 150 different languages. This diversity is one of Malmö’s key assets and creates the basis for a rich cultural life. It also equips Malmö to perform well in an ever-more globalised world. It is a large regional employer with a strong profile in social welfare and sustainable development and a commitment to providing high-quality services.

The conference is sponsored by Clarion Hotel & Congress Malmö Live

2nd International Young Carers Conference

“Every Child has the right to ...”

Monday 29th May

08.00 Registration

10.00–11.15 Opening plenary

High Live 1



Chair: Elizabeth Hanson, Professor Linnaeus University & Research Director Swedish Family Care Competence Centre, Sweden and Vice-President, Eurocarers

- Welcome to Region Skåne, Anders Åkesson, Deputy Governor and Malmö City, Carina Nilsson, Deputy Mayor
- Lena Hallengren, Chair of the Swedish Parliament Standing Committee on Education
- Saul Becker, professor and Pro Vice-Chancellor, University of Birmingham, UK
- Theo Gavrielides, Professor, The IARS International, Institute, London



Lena Hallengren
Foto Victor Svedberg



Saul Becker



Theo Gavrielides

Exhibition, Refreshment and Networking

11.45–13.15 **1. Themed Seminars**

- See outline Themed seminars
- 1.1. Promoting health and welfare
 - 1.2. Resilience
 - 1.3. Evidence-based support
 - 1.4. A rights-based perspective
 - 1.5. Other seminars

Buffet, Lunch, Exhibition and Networking

14.15–15.45 **2. Themed Seminars**

- See outline Themed seminars
- 2.1. Promoting health and welfare
 - 2.2. Resilience
 - 2.3. Life opportunities
 - 2.4. Evidence-based support
 - 2.5. A rights-based perspective
 - 2.6. Health and Social Care systems

Exhibition, Refreshment and Networking



16.15–17.45 Themed Plenaries

High Live 1 Promoting health and welfare



Chair: Endre Dahlen Bjørnstad, BarnsBeste (Childrens Best interests), a National competence network for children as next of kin/young carers in Norway

Developmental trauma: Regulation as the key concept in a new psychology of trauma, Dag Nordanger, specialist psychologist and researcher at the Regional Centre for Child and Youth Mental Health and Child Welfare (RKBU Vest) and Resource Centre about violence, traumatic stress and suicide prevention (RVTS Vest) in Norway

Young Adult Carers in the United Kingdom and United States: Identity, Choices & Life Paths, Lewis Feylyn, University of Birmingham, United Kingdom (150)

Young Carers and Young Adult Carers Research in Switzerland – first results and practice tool for professionals, Leu Agnes, Frech, Marianne, Careum Research, Research Department Kalaidos University of Applied Sciences Zürich, Switzerland (124)

Young carers in Italy: an overview, Licia Boccaletti – Anziani e non solo soc. coop., Italy

High Live 2

Health and social care systems, collaboration

Chair: Anil Patil, Carers Worldwide

Empowering youth professionals to support young carers – the experiences of the European EPYC project, Benjamin Salzmänn, Diakonisches Werk Berlin Stadtmitte e.V. project “Pflege in Not”, Germany (172)

Together we are strong: JMZ PRO, network for professionals in young carers services, Jonker Els, JMZ PRO (network for professionals in young carers services) and the Dutch Association for Youth Health Care, Netherlands (160)

Making a Step Change: Putting it into Practice ‘A partnership project managed by Carers Trust and The Children’s Society UK’, Harper Michelle, Action for Carers, Surrey Young Carers, UK

Immigrant children of mentally ill parents: The need for partnership between mental health services and religious leaders. Mekonen Leoul. Center for Child and Adolescent Mental Health, Eastern and Southern Region Noway (RBUP Øst og Sør). Norway (209)

18.00–19.30 Civic Reception at Malmö Live hosted by the Regional Council in Kalmar County and Linnaeus University

Lena Granath, member of the Board of Directors, the Regional Council in Kalmar County and contact politician SFCCC

Pauline Johansson, deputy head, Department of Health and Caring Sciences, Linnaeus University and researcher Swedish Family Care Competence Centre

Tuesday 30th May

08.00 Registration (for newly arrived attendees), Exhibition and Networking

09.30–11.00 Plenary, Childrens rights and making their voices heard

High Live 1



Chair: Stecy Yghemonos – Executive Director, Eurocarers

- Tinna Rós Steinsdóttir, Eurochild's Child Participation Officer
- Elizabet Näsman, Professor Uppsala University
- Dr Tim Moore, Senior Research Fellow at the Institute of Child Protection Studies at the Australian Catholic University and immediate past president of Carers Australia

Exhibition, Refreshment and Networking

11.30–13.00 **3. Themed Seminars**

- See outline Themed seminars
- 3.1. Promoting health and welfare
 - 3.2. Life opportunities
 - 3.3. Evidence-based support
 - 3.4. Other seminars
 - 3.5. Övriga skandinaviska seminarier
 - 3.7. Young Carers round table

Buffet, Lunch, Exhibition and Networking

14.00–15.30 **4. Themed Seminars**

- See outline Themed seminars
- 4.1. Promoting health and welfare
 - 4.2. Life opportunities
 - 4.3. Evidence-based support
 - 4.4. Innovation och technology enabled care and support
 - 4.5. Other seminars
 - 4.6. Övriga skandinaviska seminarier

Exhibition, Refreshment and Networking

16.00–17.30 Plenary, Young Carers report from Round Table

High Live 1



Chair: Elizabeth Hanson and Lennart Magnusson, Linnaeus University & Swedish Family Care Competence Centre, Sweden

- *Creating things we wish existed: programs run by young carers for other young carers.* Buchner Madeleine, Little Dreamers Australia (180)
- *Future of Young Carers in The Netherlands. Co-Designing from a Young Carers perspective.* Frans van Zoest (key presenter) & Henk Herman Nap, Expert Innovation & Research, Vilans (National Institute for Long Term Care) The Netherlands (171)

Exhibition and Networking

19.00 Conference Dinner hosted by Malmö City and Region Skåne

Rita Jedlert, Acting Director of health and medical care, Region Skåne

Annelie Larsson, Head of the Disability Support Department, Malmö City

Wednesday 31st May

08.00 Registration (for newly arrived attendees), Exhibition and Networking

09.00–10.30 **5. Themed Seminars**

See outline Themed seminars

- 5.1. Promoting health and welfare
- 5.2. Health and Social Care systems
- 5.3. Other seminars

Exhibition, Refreshment and Networking

11.00–12.30 **Closing Plenary**

High Live 1



Chair: Elizabeth Hanson and Lennart Magnusson, Linnaeus University & Swedish Family Care Competence Centre, Sweden

- Dr Yongjie Yon, World Health Organization
- Ingvar Nilsson, Economist, *Too expensive – but what? To act or not to act?*
- Patil Anil, Carers Worldwide, *Every Child has the Right... speaking up for young carers in low-income settings* (159)

Concluding comments

- Young Carers
- Stecy Yghemonos – Executive Director, Eurocarers
- Dr Tim Moore, Senior Research Fellow at the Institute of Child Protection Studies at the Australian Catholic University and immediate past president of Carers Australia

Buffet, Lunch, Exhibition and Networking

13.20 **Exhibition closes**

Themed Seminars – Monday 29th May

11.45–13.15 (*delegates should choose one*)

1.1. Promoting health and welfare

High
Live 1



1.1.1 Promoting health and welfare

Chair: Arvid Karsvall, researcher/facilitator, Swedish Family Care Competence Centre

Interventions to promote psychological health and well-being in children of parents who are in contact with adult psychiatric services. Axberg Ulf & Priebe Gisela, Department of Psychology, University of Gothenburg and Gisela Priebe, Department of Psychology, Lund University, Sweden. (184)

The needs of families with caregiving children and adolescents. A whole family perspective. Hauprich Julia & Martin Nagl-Cupal. University of Vienna, Department of Nursing Science, Austria. (130)

Young carers: growing up with chronic illness in the family. A Systematic Review from 2007–2015. Knecht Christiane, Chikhradze Nino, Metz Sabine. Witten/Herdecke University, Faculty of Health, School of Nursing Science, Germany. (137)

Managing chronic illness in the family – young carers in Germany. Metz Sabine¹, Galatsch Michael¹, Ostermann Thomas², Sibylle Robens². Witten/Herdecke University, Faculty of Health, ¹School of Nursing /²School of Psychology, Germany. (105)

Live 14 1.1.2. Promoting health and welfare

Chair: Elise Petit, ECARES, Brussels University & Fratri-Ha, Belgium

'FratriHa' - a small non-profit Brussels based organization that supports siblings of people with mental disability, Elise Petit and Eléonore Cotman, co-founders of Fratri-Ha, Belgium.

What is it like to be a sibling of a child with a disability? – a study using photo-elicitation. Peddar Jenny. University of Portsmouth, UK. (115)

Development work regarding child perspective and a higher knowledge around children, adolescents and young adults as next of kin in the Oncology Center. Öhlén Jenny. Region Gävleborg, Sweden (County Council in Gävleborg) Oncology center, Palliative unit, The Palliative team Bollnäs/Ovanåker, Sweden. (200)

Sibling supporters' experiences of giving support to siblings with a child with cancer. Jenholt Nolbris Margaretha. Institutionen för vårdvetenskap och hälsa, Göteborgs universitet, Sweden. (133)

Young Carers in Norway: Children of patients with severe illness or substance abuse, their caring activities and outcome. Kallander Ellen Katrine. Department for Research and Development, Mental Health Services, Akershus University Hospital, Norway. (156)

High Live 4 1.1.3. Främja hälsa och välbefinnande

Moderator: Marie Nyman, handläggare, Socialstyrelsen i Sverige

Når foreldre har rusmiddelproblemer – studie av Chat logg med barn og ungdom som er pårørende. Faugli Anne. Vestre Viken, Norge. (28)

"Når jeg ser han får jeg sånn stikk i hjertet" Resultater fra en kvalitativ levekårsstudie Barn og ungdom som har foreldre med rusmiddelproblemer. Kufås Elin. EK: Vestre Viken (Hospital Trust) Klinikk for Psykisk helse og Rus. MS:Organisasjonen barn av rusmisbrukere (BAR), Norge. (29)

Pulje til Behandlingstilbud til børn og unge fra familier med stof- og alkoholproblemer – Hvordan evaluerer vi? Lund Malene. Socialstyrelsen i Danmark. (56)

Børnefamilier med alkoholproblemer. Ser vi dem? Når vi dem med støtte og behandling? En tværgående analyse i Vejle Kommune og oplæg til udviklingsplan. Aalbæk Tina. Vejle Kommune, Danmark. (6)

Themed Seminars – Monday 29th May

11.45–13.15 (*delegates should choose one*)

1.2. Resilience

**High
Live 2**

1.2.1. Resilience

Chair: Anil Patil, Carers Worldwide

“Supporting Young Carers through a family and systemic approach”. Cedric Roulent & Dupont Julie. Aidants Proches Jeunes, Belgium. (157)

Resilience in children and families when a parent has cancer – an intervention study. Hauskov Graungaard Anette. Research Unit and Section of General Practice, Institute of Public Health, University of Copenhagen, Denmark. (163)

Live 4

1.2.2. Resiliens – återhämtning

Moderator: Charlotte Ugglå, programansvarig, Socialstyrelsen i Sverige

Handlingsplan för barn i missbruksmiljö – tidig upptäckt och förebyggande insatser i skolan. Stenhammar Christina & Malmberg Karin. Sociologiska institutionen Uppsala universitet och Regionsförbundet i Uppsala län/FoU-stöd och Uppsala och Enköpings kommun, Sweden. (204)

Snak om det – Børn som pårørende. Snak om det. Glistrup Karen & Smed Bettina. Danmark. (57)

“Nånting Saknas” Hur ungdomar som förlorat en förälder i cancer hittar stöd. En IPA analys. Nilsson Doris & Johan Näslund. Barnafriid – Nationellt kunskapscentrum Linköpings universitet. Sverige. (59)

IOGT-NTOs Juniorförbund, Junis, och Örebro universitet i ett samarbete för att stärka barns resiliens. Eriksson Charli, Örebro universitet & Henriksson Barbro, Junis, Sverige. (32)

1.3. Evidence-based support

**High
Live 3**

Chair: Pauline Johansson, Deputy Head of Department Linnaeus University & researcher/facilitator Swedish Family Care Competence Centre

To Implement Systematic Follow Up – Challengers and Experiences from a Case Study. Johansson Pauline & Furen-bäck Ingela & Carlsund Åsa, Linnaeus University and The Swedish Family Care Competence Centre, Sweden. (158)

BTI- Better Interdisciplinary Cooperation. A practical inspirational model focused on the child’s development and the parents client participation. Bratteteig Inger Lise. Haugesund kommune. Norway. (213)

Parents with ADHD and/or Autism: Consequences for the child and methods for support, a systematic review. Janes-lätt Gunnel & Afsaneh Roshanai. Department of Public health and Caring Sciences, Disability and Habilitation, Uppsala University, Sweden. (179)

Towards a monitoring strategy of young carers in Flanders. Bronselaer Joost & Vandezande Veronique. Department of Welfare, public health and family, Flemish government. Belgium. (224)

1.4. A rights-based perspective

Live 8

Chair: Ann-Kristin Ölund, practitioner/facilitator, Swedish Family Care Competence Centre

Children as relative at the Thoracic intensive care unit, Sahlgrenska University Hospital. Andersson Monika & Backlund Jansson Erika. Västra Götalandsregionen Sahlgrenska Universitetssjukhuset, område 6, Thorax, Thorax-intesiven, Sweden. (202)

Children as next of kin in Intensive Care. Slettmyr Anna. CIVA Karolinska University Hospital. CIVA, Central Intensive Care Unit, Karolinska Hospital, Solna, Sweden. (178)

Children as dependents in emergency situations. Bergem Anne Kristine. BarnsBeste – nasjonalt kompetanse-nettverk for barn som pårørende, Norway. (118)

Themed Seminars – Monday 29th May

11.45–13.15 (*delegates should choose one*)

1.5. Other seminars

- Live 10** Chair: Francesco Barbabella, researcher, Linnaeus University & Swedish Family Care Competence Centre
Obscuring the child caregiver: historical explanations of the political and social erasure of young carers in the United States. Olson Elizabeth. University of North Carolina – Chapel Hill, USA. (148)
Unacknowledged Caregivers in the United States: A review of young carer research with implications for future directions. Kavanaugh Melinda S. Helen Bader School of Social Welfare. University of Wisconsin – Milwaukee. USA. (149)
Experiences of Young Carers in Sweden. Nordenfors Monica & Charlotte Melander. Department of Social Work, Gothenburg University, Sweden. (147)
Professional's awareness on Young Carers & Young Adult Carers in Switzerland. Leu Agnes & Corinna Jung. Careum Research, Research Department Kalaidos University of Applied Sciences Zürich, Switzerland. (123)

Themed Seminars – Monday 29th May

14.15–15.45 (*delegates should choose one*)

2.1. Promoting health and welfare

**High
Live 2**

2.1.1 Promoting health and welfare

Chair: Emilie Normann Hovgaard, project officer, Centre for Children, Youth and Families, National Board of Social Services Denmark

When broken relationships become the norm – children wisely stop expecting them. Søndergaard Elisabeth. The PhD-project is carried out in collaboration between The Office for Quality and Development, Region Zealand, and the Research Unit for General Practice, Copenhagen University, Denmark. (153)

Wellbeing amongst of children with an incarcerated parent. Oldrup Helene. SFI, Denmark. (161)

Live 13

2.1.2 Promoting health and welfare

Chair: Marie Nyman, handläggare, Socialstyrelsen i Sverige

Children and youth in families with alcohol and drug related problems – BRUS, a collaboration between 11 Danish municipalities. Bjørn Runa & Maja Treebak. Projekt BRUS – Børn og unge i familier med rusmiddelproblemer, Denmark. (113)

Childhood experience of parental alcohol-related disorders and depression and suicidal behaviour in young adulthood – a Swedish national cohort study. Berg Lisa. Centre for Health Equity Studies, Stockholm University/ Karolinska Institutet, Sweden. (173)

Live 4

2.1.3. Främja hälsa och välbefinnande

Moderator: Ritva Gough, ordförande i styrgruppen & forskare/möjliggörare, Nationellt kompetenscentrum anhöriga, Sverige

Treffpunkt, møteplass for barn som pårørende og etterlatte. Værholm Randi. Kreftforeningen, Norge. (36)

Hälsa och välbefinnande hos barn och ungdomar som har en förälder med progredierande neurologisk sjukdom. Stefan Nilsson. Institutionen för vårdvetenskap och hälsa, Göteborgs universitet, Sverige. (52)

Barn som pårørende – mellom foreldres sykdom og egen helse. Betydning av helseperspektiv for helsefremmende arbeid rettet mot barn som pårørende. Romedal Signegun & Hege Forbech Vinje. Institutt for helsefremmende arbeid, Høgskolen i Sørøst-Norge. (22)

Att möta unga närstående där de är – på nätet. Joneklav Johanna. Nära Cancer. Sverige. (66)

2.2. Resilience

**High
Live 3**

2.2.1 Resilience

Chair: Stefania Buoni, Italy, co-founder of My Blue Box web portal, international speaker, ambassador and trainer about Copmi and Young Carers

OMSORG – Dealing With Bereavement Integrating Grief Groups for Bereaved Children in Public School Settings in Denmark. Bøge Per. Danish Cancer Society, Denmark. (128)

Every Child has the Right to Say Goodbye. Widén Lars. Bartraumateamet, BUP, Vrinnevisjukhuset, Norrköping, Sweden. (217)

All young carers should be seen not only for their challenges but also for their skills and values. "A Young Carer with a mentally ill father and a professional reflect together on her story changing from a story of fear to a story of strength". Nordenhof Ingelise & Zwinge Mathilde. Therapy & Supervision. Danmark. (221)

Themed Seminars – Monday 29th May

14.15–15.45 (*delegates should choose one*)

High
Live 4

2.2.2 Resilience – återhämtning

Moderator: Siri Gjesdahl, leder, Barns Beste Nasjonalt kompetanse nettverk for barn som pårørende, Norge
De vigtige forældre for barnets resiliens. Hougaard Sennicksen Ditte. Aalborg Universitetshospital – Psykiatrien, Danmark. (27)

Samtalegrupper for børn og unge – en indsats til børn og unge af veteraner med psykiske efterreaktioner. Wedel Gjelstrup Julie and Bonde Pollmann Jeanette. Veterancentret, Forsvarets Personalestyrelse. (60)

Grupper for barn som pårørende – et resiliencestykende tiltak. Lindgren Per Øyvind, Eli Valås Hilde Anette Sirås Myran, Otto Stormyr, Kristin Elise Løberg. Søgne kommune/Trondheim kommune, Norge. (14)

Att bygga bärande relationer – om att vara en viktig vuxen i barns och ungdomars liv. Mattila Lasse. Lasse Mattila AB, Sverige. (1)

2.3. Life opportunities

High
Live 1



Chair: Monique Jacques, Finance and admin consultant in Brussels, former young carer and champion of recognition of carers' skills.

Young Adult Carers: Impacts on Education and Health. Sempik Joe & Becker Saul. University of Birmingham, UK. (146)

Well-being at school and absenteeism of young carers. de Roos Simone & de Boer Alice. The Netherlands Institute for Social Research (SCP), The Hague, The Netherlands. (165)

“Because they care”: Understanding pathways to classroom concentration problems among HIV-affected children in western Kenya. Skovdal Morten. University of Copenhagen, Denmark. (167)

Young Carers and the Need for Interdisciplinary Cooperation. Kaiser Steffen & Knot-Dickscheit Jana & Huyghen Anne-Marie, Spittel Anna-Maria & C. Schulze Gisela. Carl von Ossietzky University Oldenburg, Department for Special Needs Education and Rehabilitation/University of Groningen, Department of Special Needs Education and Child Care, Germany. (112)

2.4. Evidence-based support

Live 10

Chair: Vibecke Ulvær Vallesverd, Adviser, BarnsBeste (Childrens Best interests), a National competence network for children as next of kin/young carers in Norway

Involving Children as next of kin in adult Palliative care is a crucial challenge – The children's rights in focus. Söderbäck Maja. Mälardalen University, Sweden. (193)

Involving children as next of kin in adult palliative care is a crucial challenge evolving local action plans – a learning process. Asp Margareta. Mälardalen University, Sweden. (195)

Involving children as next of kin in adult palliative care is a crucial challenge – Making the child as next of kin visible for promoting health. Karlsson Avelin Pernilla. Mälardalen University, Sweden. (194)

Involving children as next of kin in adult palliative care is a crucial challenge – a follow up study. Beijer Ulla. Research and Development in Sörmland and Karolinska Institute. (196)

Themed Seminars – Monday 29th May

14.15–15.45 (*delegates should choose one*)

2.5. A rights-based perspective

Live 14

Chair: Francesco Barbabella, researcher, Linnaeus University & Swedish Family Care Competence Centre

A gap between the intention of the Swedish law and interactions between nurses and children of patients in the field of palliative oncology – The perspective of nurses. Karidar Hakima¹, Åkesson Helene², Glasdam Stinne³.

1) Palliative and Advanced Homecare (ASIH) Lund, 2) Home Nursing, Ystad,

3) Integrative Health Research, Department of Health Sciences, Lund University, Sweden. (110)

Overcoming structural policy, legal and service gaps for young carers: The situation in Italy. Barbabella Francesco. Linnaeus University, Sweden. (185)

“A model on how to converse with children as next of kin and young carers, based on a child rights perspective.” Lundström Mattsson Åsa. Stiftelsen Allmänna Barnhuset, Sweden. (201)

2.6. Health and Social Care systems

Live 8

Chair: Merike Hansson, Programme Officer, The National Board of Health and Welfare Sweden

Children as dependents in difficult events. Hansson Merike. The National Board of Health and Welfare, Sweden. (168)

Psychiatric patients with children under 18 years of age – Interagency collaboration with social services and child and adolescent psychiatry. Afzelius Maria & Priebe Gisela. Malmö Högskola/Lunds universitet, Sweden. (191)

Parents’ Experiences of Caring Responsibility for Their Adult Child with Schizophrenia. Hellström Muhli Ulla & Blomgren Mannerheim Ann & Siouta Eleni. Department of Sociology, Uppsala University/Karolinska Institute, Division of Nursing, Department of Neurobiology, Care Science and Society/Department of Learning, Informatics, Management and Ethics (LIME), Karolinska Institute/Sophiahemmet University, Sweden. (169)

Themed Seminars – Tuesday 30th May

11.30–13.00 (*delegates should choose one*)

3.1. Promoting health and welfare

Live 10 3.1.1 Promoting health and welfare

Chair: Vibecke Ulvær Vallesverd, Adviser, BarnsBeste (Childrens Best interests), a National competence network for children as next of kin/young carers in Norway

“See me, talk to me and listen to me– Children as relatives at an oncological ward”. Golsäter Marie. Region Jönköpings Län, Hälsohögskolan Jönköping, Sweden. (197)

Rememberance day for children as next of kin. Hakima Karidar & Greczanik Eva. ASIH-Lund/ Palliativ vård, Sweden. (203)

The joy of doing the Beardslee Family Intervention – some key issues. Cederström Anita & Demetriades Anna, Linnaeus University, Sweden. (218)

Live 11 3.1.2. Promoting health and welfare

Chair: Ann-Kristin Ölund, practitioner/facilitator, Swedish Family Care Competence Centre

Siblings as young carers of children or adolescents with a chronic illness: A particular subpopulation.

Christiane Knecht¹, Claudia Hellmers², Sabine Metzging¹. ¹Witten/Herdecke University, Faculty of Health, School of Nursing Science, ²Osnabrück University of Applied Sciences, Faculty of Business Management and Social Sciences, Research Group FamLe – ‘Family health in the lifecourse’, Osnabrück, Germany. (136)

Support groups for children and youngsters living with a parent with dementia. Lind Ida. Alzheimerforeningen (The Danish Alzheimer Association), Denmark. (108)

I was a young carer myself. Jonker Els. AJN, the Dutch Association for Youth Health Care, Netherlands. (182)

Information to children as next of kin in radiation departments in Norway, is it good enough? Farstad Kristin. HMR Ålesund Hospital, Radiation Therapy Department. Norway. (226)

High Live 4 3.1.3. Främja hälsa och välbefinnande

Moderator: Marie Nyman, handläggare, Socialstyrelsen i Sverige

Små barn i riskzon – livsvillkor och hälsa i ett svenskt län. Köhler Marie. Kunskapscentrum barnhälsovård, Region Skåne, Sverige. (47)

ALHVA-hembaserat, verksamhetsövergripande arbete riktat till späda och små barn och deras föräldrar. Lindberg Annelie & Hagström Birthe. Malmö Stad, Sverige. (17)

Är det kört nu? – Nej! men hur identifierar vi sörjande barns behov och säkerställer att de får adekvat stöd. Catharina Richter & Kjeller Annika. Randiga huset. Sverige. (67)

Barnespor for helsepersonell. Melkeraaen Helga & Mette Grytten. Kompetansesenter rus – Midt-Norge, Lærings- og mestringssenteret, Norway. (69)

High Live 2 3.1.4. Främja hälsa och välbefinnande

Moderator: Ritva Gough, ordförande i styrgruppen & forskare/möjliggörare, Nationellt kompetenscentrum anhöriga, Sverige

Det utsagda mellan barn och föräldrar. Stenhammar Ann-Marie. Handikappförbunden, Sverige. (23)

Konflikter mellom foreldre/foresatte har alvorlige konsekvenser for barn. Grav Siv & Juul Else M & Aune Tore. Nord Universitet. Norge. (16)

Då kan ju inte jag hjälpa min mamma! Beskrivning av en lyckosam metod. Lewerth Lars & Helen Olsson. Hela Människan Uppsala Län/ Childrens Program Sverige. (65)

Min resa fram tills idag – som lillasyster till en storebror med en svår CP-skada från födseln. Lerner Jessica, Sverige. (68)

Themed Seminars – Tuesday 30th May

11.30–13.00 (*delegates should choose one*)

3.2. Life opportunities

Live 8

Chair: Francesco Barbabella, researcher, Linnaeus University & Swedish Family Care Competence Centre

Children and young people with a parent with addiction problems in school – I did not go so much to school. When I went to school, I could not concentrate – type. Näsman Elisabeth & Alexanderson Karin. Sociological institution Uppsala universitet, Sweden. (102)

Young Carers and Education in Germany. Kaiser Steffen & Gisela C Schulze. University of Oldenburg, Germany. (103)

Combining care responsibilities with a bachelor study. Research among young carers at the Amsterdam University of Applied Sciences. Kwekkeboom Rick. Amsterdam University of Applied Sciences, Community Care research group, Netherland. (132)

3.3. Evidence-based support

**High
Live 1**



Chair: Pauline Johansson, Deputy Head of Department Linnaeus University & researcher/facilitator Swedish Family Care Competence Centre

A qualitative evaluation of the Austrian's Youth-Red Cross "Juniorcamp". Prajo Nataša & Nagl-Cupal Martin. University of Vienna, Department of Nursing Science, Austria. (134)

Support for Children as Next of Kin and Systematic Follow up – Group Leaders' and Managers' Perspectives within Non-profit Organizations in Sweden. Johansson Pauline & Carlsund Åsa. Linnaeus University, Swedish Family Care Competence Centre, Sweden/Mid Sweden University, Sweden. (106)

Evaluating the effect of therapy for children, teens and young adults living with a seriously ill parent. Stigaard Tølbøll Marie. The Danish Counseling and Research Center for Grieving Children, Teens and Young Adults (DCRC), Denmark. (138)

Prevention interventions among children to parents with addiction problems, mental illness, what's the impact on children's mental health and protective factors. Jonsson Ann-Cristine, Public Health Agency of Sweden, Department of Knowledge Development, Unit for Mental Health, Children and Youth. (219)

3.4 Other seminars

Live 13

Chair: Emilie Normann Hovgaard, project officer, Centre for Children, Youth and Families, National Board of Social Services Denmark

Unheard Voices: Interviewing Parentally Bereaved Danish Students' on their Experiences and Perceptions of the Support Received Following the Return to School. Lytje Martin. The Danish Cancer Society, Denmark. (131)

Not your ordinary superhero: diagnosed with Asperger's and severe mental illness, a mother's journey of embracing the unexpected. Nestlerode Elizabeth. Child and Family Connections, Inc.USA. (154)

Cumulative disadvantage: A look at the educational and employment-based costs of youth-based caregiving via a sample of Canadian young carers. Vivian Stamatopoulos, York University – Toronto, Canada. (216)

3.5 Övriga skandinaviska seminarier

**High
Live 3**

Moderator: Charlotte Ugglå, programansvarig, Socialstyrelsen i Sverige

Barn som anhöriga i migrationskontext – webbutbildning till baspersonal om hur man kan stödja barn och familj med migrationserfarenhet till återhämtning och nyorientering. Edlund Ann-Sofie & Assel Karima. Transkulturellt Centrum, Stockholms läns landsting, Sverige. (30)

Web-univers til støtte af børn og unge som pårørende. Engelbrekt Preben. Børn, Unge & Sorg, Danmark. (20)

I skuggan av en sjukdom Hur utformar vi ett stöd som når generation Z? Boberg Katarina & Hansen René Bo. Ordlek i Helsingborg AB/Nordstjerne Film og TV, Sverige. (24)

Se meg lærer! Værholm Randi. Kreftforeningen, Norge. (45)

3.6. Young Carers round table

Live 14

This round table is exclusively for young carers attending the conference. By invitation only

Themed Seminars – Tuesday 30th May

14.00–15.30 (*delegates should choose one*)

4.1. Promoting health and welfare

**High
Live 2**

4.1.1 Promoting health and welfare

Chair: Merike Hansson, Programme Officer, The National Board of Health and Welfare Sweden

Increasing awareness and knowledge of Young Carers in Germany. Lux Katharina and Eggert Simon. Centre for Quality in Care, Berlin, Germany. (207)

Initiating early support for children with a seriously ill parent in a hospital setting. Halling Kehlet Kristine. Videnscenter for Patientstøtte – Center for Patient Experience and Evaluation, Denmark. (139)

A new successful method for detecting child maltreatment based on parental characteristics. Diderich-Lolkes de Beer Hester. Medical Center Haaglanden, Netherlands. (120)

Innovative solutions developed by young carers – cooperation between the non profit and public sectors. Dahlgren Lisa. Maskrosbarn, Sweden. (198)

Live 10

4.1.2. Promoting health and welfare

Chair: Francesco Barbabella, researcher, Linnaeus University & Swedish Family Care Competence Centre

Health professionals and the young children of their dying patients. Johnsen Hogstad Ingrid. Høgskolen i Molde/ Molde University College, Norway. (129)

OmSorg – Dealing with Bereavement – integrating Bereavement Response Plans in all Danish Public Schools and Kindergartens. Bøge Per. Danish Cancer Society, Denmark. (127)

Sometimes life hurts – Support groups for bereaved families. Berg Christina. Stiftelsen Bräcke Diakoni; Hospice Helhetsward, Sweden. (107)

Live 14

4.1.3. Promoting health and welfare

Chair: Claire Champeix – Policy Officer, Eurocarers

A support group intervention for siblings and parents of children with chronic health conditions. Haukeland Yngvild. Frambu Comptence Centre for Rare Disorder and Departement of Psychology, University of Oslo, Norway. (140)

Children´s perspectives on their siblings with rare disorders – A qualitative study of 11 support group sessions. Fjermestad Krister W. Department of psychology, University of Oslo, Norway & Frambu Resource Centre for Rare Disorders, Norway. (142)

Emotional dialogues between parents and siblings of children with chronic disorders. Vatne Torun M. Frambu Comptence Centre for Rare Disorder and Departement of Psychology, University of Oslo, Norway. (144)

Do support groups act supportive? Emotional dialogue in support groups for siblings of children with rare disorders. Vatne Torun M. Frambu Comptence Centre for Rare Disorder and Departement of Psychology, University of Oslo, Norway. (143)

Live 11

4.1.4 Främja hälsa och välbefinnande

Moderator: Charlotte Uggla, programansvarig, Socialstyrelsen i Sverige

Mine pårørendeegenskaper gjør meg til en ressurs – for meg selv og for samfunnet. Lied Elisabeth. Stiftelsen Kirkens Bymisjon Rogaland, Ventilene, Norge. (42)

Jag är både stark och svag – ung anhörig med demenssjuk förälder. Eriksson Jenny. Sverige. (48)

På Ågrenska tas syskon på allvar. Röjvik AnnCatrin och Astrid Emker. Ågrenska. (62)

Glädjeverkstan – clownerna på Astrid Lindgrens Barnsjukhus. Riepe Eva, Möller Anne-Marie. Sjukhusclowner i hemsjukvården – anhörigbarnen, Sverige. (64)

Themed Seminars – Tuesday 30th May

14.00–15.30 (*delegates should choose one*)

4.2. Life opportunities

Live 8

Chair: Ailsa Tweedie, Carers Trust Scotland, Young Adult Carer Voice' project & board member of the Board of Directors, Lanarkshire Carers Centre

Follow-up of children as next of kin to severely ill parents with migrant background. Ali Warsame. NAKMI. Norwegian Center for minority health research, Norway. (126)

“superhands” – Support of Young Carers in Austria. Desbalmes Claudia. Johanniter NÖ Wien Gesundheits- und soziale Dienste mildtätige GmbH, Österreich, Austria. (125)

Young adult carers campaigning for better education. Chloe Alexander. University of Birmingham. (145)

The role of adult social care in improving outcomes for young people who provide unpaid care. King Derek, Brimblecombe Nicola, Knapp Martin, Lombard Daniel. Personal Social Services Research Unit, London School of Economics. United Kingdom. (223)

4.3. Evidence-based support

Chair: Anit Patil, Carers Worldwide

Implementation and systematic follow-up of family-focused care in a neurological department. 3 different methods of support. What works in practice? Åkerlund Kerstin och Meijer Karolina. Karolinska universitetssjukhuset, Neurologiska råd- och stödenheten, Sweden. (211)

Development and testing of a family based support program for young carers and their families in Austria. Nagl-Cupal Martin & Hauprich Julia. University of Vienna, Department of Nursing Science, Austria. (135)

Social services support groups for children as next of kin – methods and goals. Furenbäck Ingela & Johansson Pauline. Linnaeus University and The Swedish Family Care Competence Centre, Sweden. (212)

Knowledge development for evidence-based support to children of parents with dependency disorders – A national, regional and local development program. Eriksson Charli. Örebro University, Sweden. (174)

4.4. Innovation and technology enabled care and support

Live 13

Chair: Arvid Karsvall, researcher/facilitator, Swedish Family Care Competence Centre

Internet-delivered information and self-management programs for children and adolescents coping with parental multiple sclerosis. Mauseth Torild & Liv Solfrid Øvstebø Berge. Norwegian Multiple Sclerosis Competence Centre, Haukeland University Hospital/Municipality of Bergen, Health services for children and adolescents, Norway. (151)

Development and validation of a risk assessment interview for children exposed to intimate partner violence and child abuse. Hultmann Ole & Eriksson Maria & Iversen Clara & Röbäck de Souza Karin. Psykologiska institutionen, Göteborgs universitet/Mälardalens högskola, Akademin för hälsa, vård och välfärd/Sociologiska institutionen, Uppsala universitet, Sweden. (176)

TEENS: Health Related Internet Gaming & Connections to Peers. Smith Carol E. University of Kansas School of Nursing, USA. (101)

**High
Live 1**



Themed Seminars – Tuesday 30th May

14.00–15.30 (*delegates should choose one*)

4.5. Other seminars

**High
Live 4**

Chair: Ritva Gough, Chairman of Board of Directors & researcher, Swedish Family Care Competence Centre
'The girl, the mother and the demons'. Margaretha Herthelius, Swedish Schizophrenia Association will show a renowned Swedish film in seminar 4.5. Vocals are in Swedish with English sub-titles. (46)

"Flickan, Mamman och Demonerna". Margaretha Herthelius, Schizofreniförbundet visar den välkända svenska filmen i seminarium 4.5. Textad på engelska. (46)

4.6. Övriga skandinaviska seminarier

**High
Live 3**

Moderator: Siri Gjesdahl, leder, Barns Beste Nasjonalt kompetanse nettverk for barn som pårørende, Norge
Psykisk syk med barn i magen. Gjervik Heldahl Elisabeth. Nordlandssykehuset, Norge. (39)

Formidling af resultater og erfaringer fra Projekt Oprust – et tilbud til unge pårørende til psykisk sårbare. Hansen Maja & Nielsen Rie Helmer. Det Sociale Netværk, Danmark. (10)

"Professionellas erfarenheter av barnperspektivet och av att genomföra Beardslees familjeintervention med familjer i psykosvården". Strand Jennifer. Psykologiska institutionen, Göteborgs universitet, Sverige. (18)

"Straffen rammer flere: Veier til mestring for barn og unge med et familiemedlem i fengsel". Holden Kjersti & Kitty Byng. For Fangers Pårørende (FFP), Norge. (25)

Themed Seminars – Wednesday 31st May

09.00–10.30 (*delegates should choose one*)

5.1. Promoting health and welfare

**High
Live 2**

5.1.1 Promoting health and welfare

Chair: Vibecke Ulvær Vallesverd, Adviser, BarnsBeste (Childrens Best interests), a National competence network for children as next of kin/young carers in Norway

Introducing and promoting the issue of children as next of kin and young carers in Finland. Heino Malla & Huh-tonen Sanna. The Central Association of Carers in Finland and The National Family Association Promoting Mental Health in Finland, Finland. (181)

Children as next of kin in the healthcare system Implementation of the provision in paragraph 2 g of the Health and Medical Services Act in a large organisation. Ramnfors Christina. Västra Götalandsregionen, Koncernkontoret, Koncernstab hälso- och sjukvård, Sweden. (199)

BørneBuddies in Copenhagen: supporting healthy children, who experience serious illness in the family, by establishing a volunteer corps of students from The Metropolitan University College. Wind Gitte & Jørgensen Gitte Kaarina & Vilstrup Dorte. Department of Nursing, Faculty of Health and Technology, Metropolitan University College, Copenhagen, Denmark. (222)

CHILDREN'S TRAUMA TEAM Acute intervention and support at traumas and losses. Widén Lars. Barntraumateamet, BUP, Vrinnevisjukhuset, Norrköping, Sweden. (111)

Live 8

5.1.2. Promoting health and welfare

Chair: Ann-Kristin Ölund, practitioner/facilitator, Swedish Family Care Competence Centre

How it is to be a young carer and a psychologist working in an oncology unit in a Brussels hospital-dual experiences and how they benefit each other, Mélanie Ronsse, Brussels, Belgium

Family Cohesion After Losing A Parent To Cancer As a Teenager and Long Term Health and Wellbeing. Birgisdóttir Dröfn. Palliativt Utvecklingscentrum vid Lunds Universitet och Region Skåne. The Institute for Palliative Care, Sweden. (155)

Nurses' perceptions of adolescents whose parent suffers from cancer (in progress). Tafjord Trine. NTNU, Faculty of Social Sciences and Technology Management, Department of Social Work and Health Science, Norway. (122)

Psychosocial health after the loss of a parent to cancer – young adults who participated in a support group. Lundberg Tina. Institutionen för neurobiologi, vårdvetenskap och samhälle, Karolinska Institutet, Palliativt Forskningscentrum, Institutionen för vårdvetenskap, Ersta Sköndal Högskola, Kuratorskliniken, Karolinska Universitetssjukhuset, Sweden. (192)

Live 10

5.1.3. Främja hälsa och välbefinnande

Moderator: Siri Gjesdahl, leder, Barns Beste Nasjonalt kompetanse nettverk for barn som pårørende, Norge

Manglende forankring av tidsrammer skaper hindringer i arbeidet rundt barn som pårørende. Hjelmseth Maria & Aune Tore. Nord Universitetet, Norway. (13)

Hør på meg og snakk til meg! Værholm Randi. Kreftforeningen, Norge. (43)

Ungdomar som växt upp med föräldrar med missbruksproblem bidrar till skolutveckling – "precis som när man blir inkallad på hälsosamtal till skolsystem, så kanske alla borde bli inkallade till kuratorn".

Alexandersson Karin och Lind Sofia. Sociologiska institutionen Uppsala universitet och Regionförbundet i Uppsala län/FoU-stöd och Uppsala och Enköpings kommun, Sverige. (5)

Patient och närståendeutbildning enligt laering och mestring för familjer som lever med sjukdomen MS – Utbildning med fokus på familjeperspektiv. Tauberman Margareta & Magnusson Monika. Neurologi och Rehabiliteringskliniken Centralsjukhuset Karlstad, Sverige. (11)

Themed Seminars – Wednesday 31th May

09.00–10.30 (*delegates should choose one*)

5.2. Health and Social Care systems

High
Live 1



5.2.1. Health and Social Care systems

Chair: Arvid Karsvall, researcher/facilitator, Swedish Family Care Competence Centre

Children of parents with intellectual disability: “Transforming” children’s lives. Who takes the challenge? Gudkova Tatiana. NTNU, SVT-fakultetet, Institutt for sosialt arbeid og helsevitenskap, Trondheim, Norway. (114)

Early caregiving and the impact on further life from the perspective as an adult. A literature review. Roling Maren. Witten/Herdecke University, Germany. (104)

Young carers in Sweden. Priebe Gisela & Järkestig Berggren Ulrika & Bergman Ann-Sofie & Eriksson Maria. Dep. of Psychology, Lund university/School of Social Work, Linnaeus University, Kalmar/School of Health, Care and Social Welfare, Mälardalen University, Eskilstuna, Sweden. (164)

Live 14

5.2.2 Hälsa-, sjukvårds- och socialtjänstsystem

Moderator: Lena Gustafsson, praktiker/möjliggörare, Nationellt kompetenscentrum anhöriga

Biblioteket som en arena för att uppmärksamma barn som anhöriga – Ett samverkansprojekt mellan stads-områdesförvaltning Öster i Malmö, Husiebiblioteket, Rosengårdsbiblioteket och Region Skåne. Roijer Maria, Edlund Ann & Eliasson Christoffer. Region Skåne, Kunskapscentrum barnhälsovård och Malmö Stad, Stadsområdesförvaltning Öster, Sverige. (19)

Et lykkelig ægteskab fejrer kobberbryllup. Hougaard Sennicksen Ditte. Aalborg Universitetshospital – Psykiatrien. Danmark. (26)

Erfarenheter av vägar till ökat familjeperspektiv i socialtjänst och hälso- och sjukvård. Hagberg Peter. Peter Hagbergs utbildning och implementering AB, Sverige. (53)

High
Live 3

5.2.3 Hälsa-, sjukvårds- och socialtjänstsystem

Moderator: Merike Hansson, programansvarig, Socialstyrelsen Sverige

Samverkan – hur får man till det? Trägen vinner – ett exempel från Jönköping. Andréasson Marie & Johansson Katarina. Jönköpings kommun/psykiatriska kliniken i Region Jönköpings län, Sverige. (8)

Kojan – Anhörigcentralens stöd till Barn som anhöriga i Uddevalla Kommun. Barn som anhöriga – att synliggöra och identifiera barns behov av eller möjlighet att få stöd och samtal med andra aktörer i sin vardag. Elbing Malin & Elisabeth Bergström. Uddevalla kommun, Sverige. (3)

Hur kan vi tillgodose barns behov av information, råd och stöd när en förälder är sjuk? – erfarenheter från ett förbättringsarbete på hälsocentral. Luuk Liisa & Cheruiyot Johansson Emmy, Esplanadens hälsocentral, Västervik, Landstinget i Kalmar län. Sverige. (70)

Styrkor och färdigheter som möjligheter i utbildning och arbete för unga omsorgsgivare med minoritets- och utländsk bakgrund. Pauline Johansson & Eva Nordqvist. Nationellt kompetenscentrum anhöriga och Linneuniversitetet. Sverige. (71)

5.3. Other seminars

Live 13

Chair: Anita Cederström, Linnaeus University and Swedish Family Care Competence Centre, Sweden

Early home-based support to families at risk. Björkhammar Turesson Annelie. Malmö University, Sweden. (190)

A Swedish Master Course about Children as Next of Kin. Pauline Johansson, Magnusson Lennart & Cederström Anita. Swedish Family Care Competence Centre & Linnaeus University, Sweden. (214)

“Dental examination of child victims of violence and sexual assault”. Stamnes Köpp Unni Mette. Sørlandet Hospital (Sørlandet sykehus HF – SSHF), Norway. (170)

“Scarred for life? – No!” The necessity to identify grieving children’s needs and to ensure the adequate support they are entitled to. Richter Catharina & Kjeller Annika. Randiga huset, Sweden. (225)

Main Speakers



Saul Becker, University of Birmingham, England

Professor Saul Becker is Pro-Vice-Chancellor (PVC) at the University of Birmingham, Head of the College of Social Sciences, and a member of the University Executive Board. In his PVC role he is responsible for the leadership and management of all portfolios in a College with 800 staff and nearly 10,000 students spread across four Schools (Government & Society, Social Policy, Education, and Birmingham Business School). Saul also has University-wide thematic responsibilities that include leading on Civic Engagement; supporting the University of Birmingham Secondary (Training) School; Brexit Planning; and 'Engagement for Impact' (E4I).

Saul has previously held Chairs at the universities of Loughborough, Birmingham and Nottingham before returning to Birmingham in 2014. At Nottingham (2006-14) he was Assistant Pro-Vice-Chancellor for Internationalisation; Faculty Director of Research for the Social Sciences; and Head of the School of Sociology and Social Policy.

Saul is an active researcher and passionate advocate for public engagement, with over 50 externally funded research projects as Principal Investigator; 330 publications (including 18 books); and over 210 conference papers most as invited keynote speaker. He is regarded as a world leader for research on 'young carers' – children who provide (unpaid) care to ill, disabled and other family members. He is invited around the world to talk about his research, policy, and he currently advises Governments, policy makers and professionals/service providers in a number of countries.

Saul is an Academician of the UK's Academy of Social Sciences and a Fellow of the Royal Society of Arts. He was a member of the REF 2014 Sub-panel 22 for Social Work and Social Policy (reviewing and assessing the quality of research across all UK universities), and he is a former Chair of the UK Social Policy Association. He is the Founding Series Editor for the Policy Press Understanding Welfare book series. Saul is also a qualified and Registered Social Worker. In his childhood he was a young carer.



Licia Boccaletti, Anziani e non solo, Italy

has a university degree in humanities and a master degree in nonprofit economy. She works as coordinator of international activities of Anziani e non solo, a leading Italian NGO on the topic of informal carers and one of the first organizations in the country to develop research and practices on the topic of young carers.

Licia has been involved as social researcher and trainer in the European projects TOYAC, Care-2Work and EPYC and on the national project Educare alla Cura, all focusing on young carers and regularly gives awareness rising and training sessions to youth workers, teachers and social workers on young carers related issues.

From 2010 to 2015 Licia has been a member of the executive committee of Eurocarers.



Madeleine Buchner, Little Dreamers Australia

Born and bred in Melbourne, Australia, Madeleine is an entrepreneur, social innovator and Young Carer with a passion for supporting other Young Carers. Madeleine founded Little Dreamers Australia at age 16 to support Young Carers in their 5 main risk areas: education and financial disadvantage, unemployment, social connectedness and mental health. Having supported more than 1000 families in Australia, Little Dreamers is now an internationally recognised organisation that believes in a world where Young Carers have someone to care for them. Madeleine is also a 2017 Queen's Young Leader award recipient.



Feylyn Lewis, University of Birmingham, England

Feylyn's doctoral research focuses on the identity development of young adult carers living in the United Kingdom and United States, under the supervision of Professor Saul Becker at the University of Birmingham. During Feylyn's childhood, her older brother was a carer for her and their mother who has a physical disability. While completing her doctoral research, Feylyn remains committed to raising the profile of young carers through blog writing, podcasts, and speaking engagements around the world. A native of Nashville, Tennessee in the United States and graduate of Vanderbilt University, Feylyn is a nationally certified mental health counselor.



Theo Gavrielides, Dr., The IARS International Institute, London

Since 2001, Theo have been the Founder and Director of the IARS International Institute. He is also the Founder and co-Director of the Restorative Justice for All Institute (RJ4All). Apart from the NGO and practical experience, he is also active in academia. I is an Adjunct Professor at the School of Criminology (Centre for Restorative Justice) of Simon Fraser University as well as a Visiting Professor at Buckinghamshire New University. He also served as a Visiting Professorial Research Fellow at Panteion University of Social & Political Science (Greece) and a Visiting Senior Research Fellow at the International Centre for Comparative Criminological Research (ICCCR) at Open University (UK). Theo is also the Editor-in-Chief of the peer-reviewed journals:

- International Journal of Human Rights in Healthcare
- Youth Voice Journal
- Internet Journal of Restorative Justice



Lena Hallengren, Chair of the Swedish Parliament Standing Committee on Education

Lena Hallengren is a Social Democrat Member of Parliament and MP Hallengren has represented her constituency of Kalmar since 2006. In the Swedish Parliament she is chair of the Standing Committee on Education and a member of the War Delegation. She has previously served as Vice-Chair of the Standing Committee on Health and Welfare, Chair of the Standing Committee on Transport and Communications, member of the Standing Committee on Environment and Agriculture and also as member of the parliamentary advisory committee on climate. As union secretary of the Swedish Social Democratic Youth League, SSU, she was responsible for the organization until she was appointed minister – one of the youngest so far! Lena Hallengren was minister in the government between 2002–2006 and was responsible for preschool, youth, student support, education and adult education. Before that, she led a special youth group in the Social Democratic Party and was a member of the EU’s Convention on the Future of Europe which was responsible for discussing and drafting a new EU constitution. MP Hallengren’s political journey began in Kalmar with various assignments for SSU, in local politics as a member of the municipal executive committee and as vice-chair of the municipal assembly. MP Hallengren is an educated teacher and has a strong commitment to striving for good conditions to ensure children and young people’s welfare and learning- topics which specifically engage her and which drive her in her political work. (Foto Victor Svedberg)



Elizabeth Hanson, Swedish Family Care Competence Centre and Linnaeus University

Elizabeth is Scientific Leader of ‘Nationellt kompetenscentrum anhöriga’ (The Swedish Family Care Competence Centre-SFCCC), a national centre of excellence in the field of informal care and a Professor in Health Care Sciences at the Linnaeus University, Kalmar in the south-east of Sweden. She is also Visiting Reader at the University of Sheffield, School of Nursing in the UK. Elizabeth is currently Vice-President of Eurocarers, representing the research organisations. She co-ordinates the Eurocarers Research Working Group (ERWG), which has worked together to define current research priorities concerning carers, care and caring in the EU, to influence public policy makers and EU institutions of the need for research to help inform policy and evidence based practice in the area. Elizabeth leads the current work of the ERWG which includes a Eurocarers Horizon 2020 research proposal focusing on promoting the mental health and wellbeing of young carers and an education strategic partnership initiative within the Erasmus+ programme focusing on preventing early school drop-out among young carers. Elizabeth has supervised and participated in commissioned work from the National Board of Health and Welfare Sweden focusing on a series of systematic reviews of the empirical research in the field of children as next of kin and young carers. Elizabeth is a nurse by background with long-standing interests in carer support services and interventions, quality of life of people with advanced long-standing chronic conditions and their families and empowerment in research and practice.



Michelle Harper , Carers Trust, UK

Michelle Harper has been the Manager of the largest Young Carer service in the UK since 2008. She has a BA hons in Community and Youth work, graduating from St Martins college in Lancaster in 2003. Michelle holds Chair for the Young Carers Interagency Strategy group in Surrey and forms part of the National Young Carer and Young Adult Carer National Steering group. Michelle has been at the forefront of this pioneering service, working in close partnership with the Local Authority, NHS England, Adult and Children’s Social Care, Education and Youth Support Services, to inform the law, policy and best practice in the UK.



Els Jonker

Els Jonker (1951), medical specialist in public child healthcare, is since 1979 working as child healthcare physician for children age 4-19. Although once a young carer herself, it took her more than half a decade to recognise that she and her profession had a blind spot for young carers and their parents. First step was putting 'Young Caring' on the agenda of her own professional society AJN Jeugdartsen Nederland. From then on she developed step by step into expert and ambassador on young caring, a development not possible without the support of and exchange with a variety of professionals, researchers and (former) young carers.



Agnes Leu, Careum Research, Kalaidos University of Applied Sciences, Switzerland

Agnes Leu is a Law Professor and program director of Careum Research, the research department of Kalaidos University of Applied Sciences, Department Health Sciences in Zürich, Switzerland. Agnes is a social worker and lawyer by training whose research cuts across legal, social and ethics issues. She is a highly qualified legal specialist in Public Health Law and in Social Security Law in Switzerland. Her research interests lie in the area of vulnerable patient groups and in recent years, she has focused on young carers. Agnes has collaborated actively with researchers in several other disciplines and other countries, particularly on young carers equal participation in education.



Lennart Magnusson, Swedish Family Care Competence Centre and Linnaeus University

Lennart Magnusson is Director of 'Nationellt kompetenscentrum anhöriga', (the Swedish Family Care Competence Centre-SFCCC) where he actively works with influencing evidence based policy making and practice in the field of carers, care and caring. He is an Associate Professor at the Department of Health and Caring Sciences at Linnaeus University in the south-east of Sweden. He is an engineer and specialist nurse by background. Lennart has worked with research, development and education in the area of carers for the last 20 years with a focus on e-learning and the implementation and evaluation of innovative forms of support for carers, including the use of Information and Communication Technologies. Lennart heads up a major stream of work at the SFCCC, commissioned by the National Board of Health and Welfare Sweden, which focuses on raising awareness of the situation of children as next of kin. As well, to stimulate and disseminate evidenced-based knowledge in the field and to drive evidence-based policy and practice development work in the area in partnership with diverse stakeholders at regional and national level, and with due attention to best practices at EU level and internationally. Lennart has a long-standing interest in the situation of carers and of vulnerable people with long-standing health and care needs, including innovative ways of working to improve health and care services, carer support and to enhance job satisfaction for practitioners and decision makers.



Leoul Mekonen, Regional Center for Child and Adolescent Mental Health Eastern and Southern Norway

Leoul Mekonen is director of multicultural health studies and lecturer at Regional Center for Child and Adolescent Mental Health Eastern and Southern Norway (RBUP Øst og Sør). He studied social work at Oslo University college (HiOA), Professional interpreter education at University in Bergen (UiB) and master's degree in health promotion and community care at Norwegian University of Science and Technology in Gjøvik. Leoul has background from medical anthropological research in Ethiopia. He has diverse experience from work with children and youth with minority background in Norway. He lectures at various universities and colleges to different professional groups about health care and social work with ethnic minorities and immigrants. Leoul is Ethiopian refugee and came to Norway 19 years ago as asylum seeker; he uses his own personal experiences and stories to engage students and professionals who attend his courses. In addition to his career as a lecturer, he works on several projects in a voluntary organization; Multicultural Initiative Resource Network (MiR). He conducts several dialogue based health promotion and prevention programs within different immigrant communities about female genital mutilation (FGM), forced marriage, intimate partner violence, gender equality and child rearing practices.



Dr Tim Moore, Australian Catholic University, Australia

Dr Tim Moore is Senior Research Fellow at the Institute of Child Protection Studies at the Australian Catholic University and immediate past president of Carers Australia.

In 1997, Tim established Australia's now longest running young carer support program and has had the great privilege of working with and learning from young carers ever since.

Tim has helped design and implement a number of young carer focused programs, policies and research projects and participated in national and international conferences, policy forums and debates on young carers' needs, experiences and models of support.

As a former youth worker and researcher, Tim has developed significant interest and expertise in the broad field of children's participation. He has helped design participatory processes, supporting children and young people to actively shape, facilitate, evaluate and lead projects that directly impact on their lives. His research has focused on children and young people in the child welfare, child protection, health and education systems and has strongly advocated for their expressed needs and wishes to be placed at the centre of policy and program responses.



Henk Herman Nap

Henk Herman Nap has a MSc in Psychology and a PhD in Gerontechnology. He currently works at Vilans as an expert senior researcher on innovation in eHealth and health policy and at the Technische Universiteit Eindhoven as a senior researcher. He is an associate editor of Gerontechnology Journal and Industry Liaison of the Gerontoludic Society. He worked in academics, Smart Homes, and many European AAL, H2020 and Framework projects. We should design (health) technologies that are meaningful, accessible, and non-stigmatising.



Ingvar Nilsson

Ingvar Nilsson is a national economist and a frequently hired lecturer who has figured out what exclusion costs society and the economic benefits that can be made with prevention - both from a human and economic perspective. Ingvar Nilsson has conducted numerous studies on youth in difficulty, school problems, substance abuse, mental illness, chronic disease, long-term unemployment, early intervention on children and young people, and more.



Dag Nordanger, Centre for Child and Youth Mental Health and Child Welfare – West Norway

Dag Nordanger, Dr. Psychol. and specialist in clinical child psychology, is primarily affiliated to the Centre for Child and Youth Mental Health and Child Welfare – West Norway (RKBU Vest). He also has a part-time position at the Resource Centre for Violence, Traumatic Stress and Suicide Prevention - Western Norway (RVTS-West) where he was the director for six years. He has for many years been working in the field of trauma, both with counselling, therapy, lecturing and research, and has been involved in a number of international projects and taskforces. A bulk of his earlier publications are based on studies among Ethiopian victims of trauma, and concentrate on culture bound responses and coping strategies. His latest projects and writings circle around children at risk, with a special focus on the concept of developmental trauma. He is the founder and coordinator of the Norwegian Child and adolescent complex trauma society (CACTUS), a network of experts across competence and research centres with a special interest in improving identification and assessment of children exposed to developmental trauma. In 2012 he was awarded the best article in the Journal of the Norwegian Psychological Association for the article "Complex trauma in the perspective of developmental psychology". He is a much requested speaker on this topic.



Elizabeth Näsman, Department of Sociology, Uppsala University, Sweden

Elisabet Näsman, Senior professor of Sociology at Uppsala university, is a researcher in Childhood Sociology, focusing for the last decades on children in families where the parents have problems. From a child perspective she has studied children lives in families where parents struggle with unemployment, poverty, violence, drug addiction and cognitive difficulties. Her aim is to promote an understanding of children as actors in their own life and the participatory rights this calls for. She is also teaching on children's living conditions and participation and has conducted development projects with professionals in social work with children and young people in order to improve children's options for participation.



Anil Patil, Carers Worldwide

Anil has over 20 years experience in the international development sector. He is the founder of Carers Worldwide, a charity focussed on highlighting and tackling the issues facing unpaid family carers of all ages in developing countries, a group largely unrecognised and unsupported. A carer himself, Anil's vision is a world in which the needs of every carer are met in order to achieve physical, emotional, economic and social wellbeing for each individual. Through the holistic model Anil has developed, Carers Worldwide serves as a catalyst bringing about systemic change in the work of governments, charities and other agencies so that they recognise and respond to the needs of carers in the developing world and facilitating support for individual carers and their families in the developing world, bringing them better health, wellbeing and economic security.



Tinna Rós Steinsdóttir: Eurochild's Child Participation and Network Development Officer. As a part of her role, Tinna is responsible for communication with the children and young people that Eurochild works with, and works to insure meaningful child participation in all their work. Tinna has great experience in child/youth participation, leadership training and personal development from years of involvement in the YMCA and YWCA on local level in Iceland, on European level, and on world level. She is currently a bureau member of the Advisory Council on Youth of the Council of Europe (CCJ), is involved in the European Youth Forum (YFJ) and sits on the Youth Policy Group of YMCA Europe.



Benjamin Salzmänn, Diakonisches Werk Berlin Stadtmitte e.V. Germany

Benjamin Salzmänn is a MA social worker based in Berlin Germany. He is the project coordinator of the European EPYC project (Empowering professionals to support young carers), funded by Erasmus+. Under the roof of the non profit organization Diakonisches Werk Berlin Stadtmitte e.V. he is involved in two additional projects - one being a competence center for family carers of all ages and the other being a counseling service for family carers experiencing a crisis. He is coordinating a growing network of stakeholders in Berlin who raise awareness on young carer issues and recently he set up and coordinates an online support service for young carers and young adult carers in Berlin called "echt unersetzlich...!?".



Stecy Yghemonos, Eurocarers

Stecy Yghemonos is the Executive Director of Eurocarers, the European association working for carers. A trained journalist, Stecy is an EU policy and communication specialist. Over the last thirteen years he has acted as a Project, Advocacy and Communications Director in organisations promoting and defending the reinforcement and harmonisation of domestic and foreign EU policies in the fields of press freedom, social justice, children's rights, development, health, education and vocational training. Together with the Eurocarers Steering Committee he sets the direction of the Eurocarers network, develops and oversees the implementation of the action plan. He is also responsible for the Eurocarers secretariat in Brussels as well as for its activities in the fields of network development, project management, fund raising, policy influencing, advocacy and communications.



Dr Yongjie Yon, WHO

Dr. Yongjie Yon is a Technical Officer at the World Health Organization (WHO) Regional Office for Europe. He works in the area of Violence and Injury Prevention as well as Healthy Ageing. Dr. Yon has conducted research examining abuse over the life course including elder abuse, violence against women and child maltreatment. He was a Doctoral Fellow with the Social Sciences and Humanities Research Council of Canada and received his PhD from the University of Southern California. Prior to WHO, Dr. Yon worked for the Federal Government of Canada as a Policy Analyst. Dr. Yon has published in leading journals on research relating to public health including ageism, abuse over the life course, intergenerational relations, oral health, housing and health disparities.

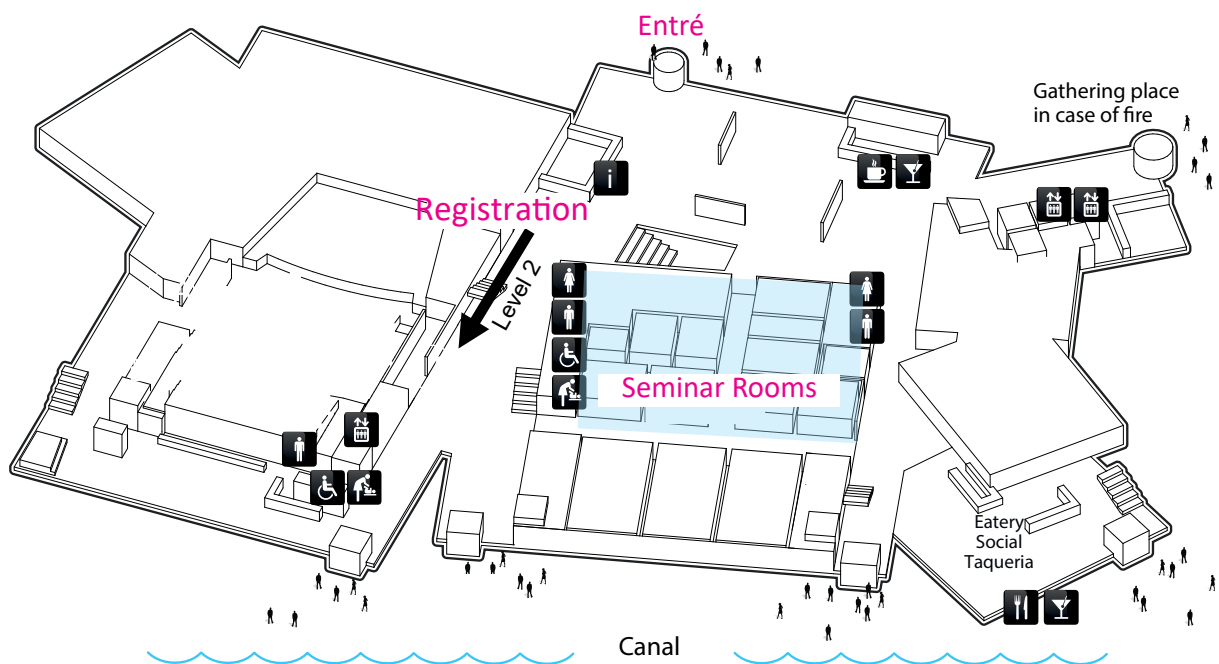


Frans van Zoest, Vilans

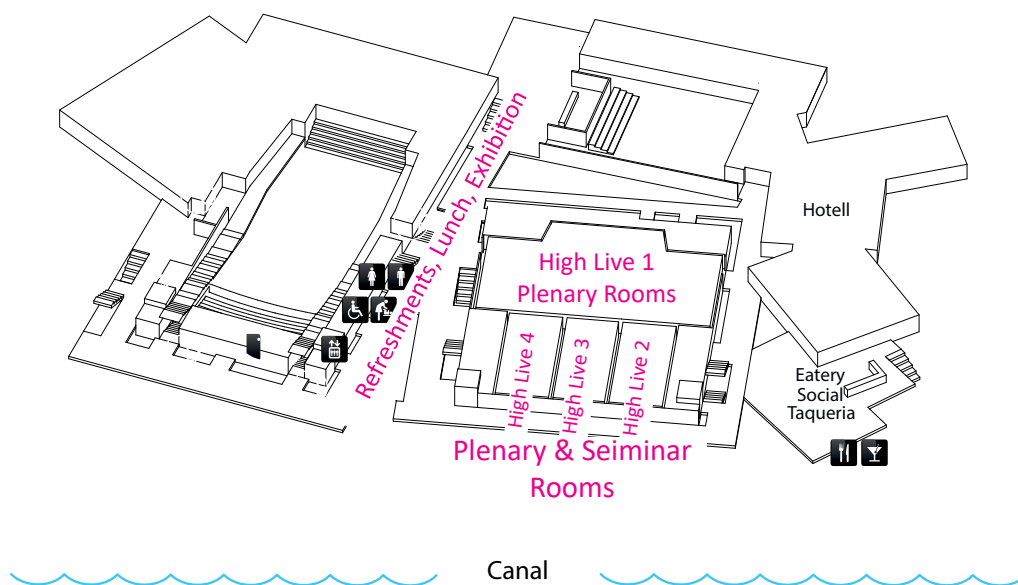
Frans van Zoest has masters in Health Science and in Public Health. He works as senior Innovation & Research at Vilans, Center of Expertise in Long Term Care in the Netherlands. He has worked for 20 years in national and international Public Health and is currently working on innovation in long term care. His work is informal care (volunteers, young carers), future trends, health Impact Bonds and innovative methods like design thinking and narrative research. He is active in Euro-carers Research Working Group.

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