ERN ITHACA
Webinar 2025

With the patient in the middle - focus on the whole family “a Norwegian model”

TUESDAY, APRIL 8, 2025 FROM 5PM TO 6.30 PM CEST

Chaired by: Heidi E. Nag

European Commission

EUROPEAN REFERENCE NETWORKS

Helping patients with rare or low-prevalence complex diseases

Project Manager Anne Hugon

2025

European Reference Networks ITHACA

Welcome – Technical points

- **We are please to be numerous > 110 registrations**
- **Webinar being recorded**

- **Thank you for**
  - Turn off your microphone and disconnect your camera
  - Raise your hand at the time of the questions and discussions
  - We will answer the questions sent in the registration form
  - A satisfaction survey will be sent to you :

- **Webinars # will be available on ITHACA's Website**
- **https://ern-ithaca.eu/webinars/**

- **Anne Hugon Project Manager ERN ITHACA - anne.hugon@aphp.fr**

Agenda

- Welcome and Introduction
  - Heidi E. Nag, Special Educational Advisor, PhD - Frambu Resource Centre for Rare Disorders, Norway
- A presentation of Frambu and the Norwegian model
  - Kristian Kristoffersen, director at Frambu - Frambu Resource Centre for Rare Disorders, Norway
- Parents
  - Torun Vatne, Doctor of Psychology - Frambu Resource Centre for Rare Disorders, Norway
- Grandparents and caring for the care givers
  - Tonje Elgsås, Psychologist - Frambu Resource Centre for Rare Disorders, Norway
- Siblings
  - Krister W. Fjermestad, Doctor of Psychology - Frambu Resource Centre for Rare Disorders, Norway

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A presentation of Frambu and the Norwegian model

Kristian Kristoffersen

Director/PhD

2025

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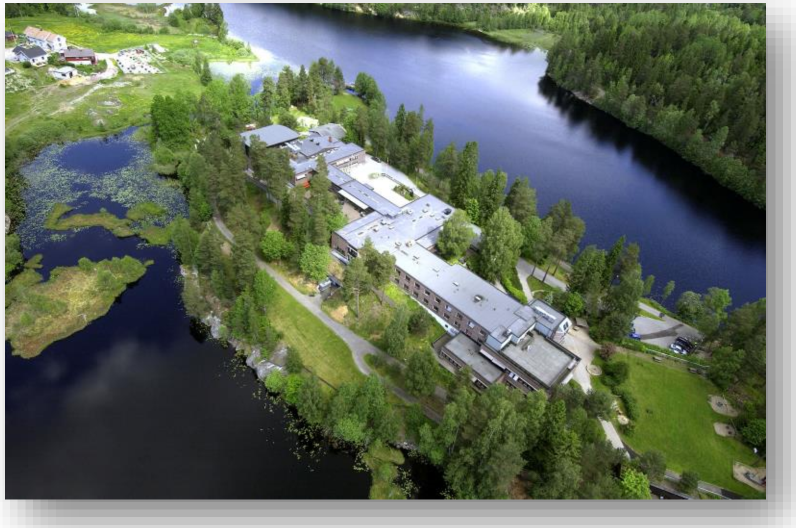
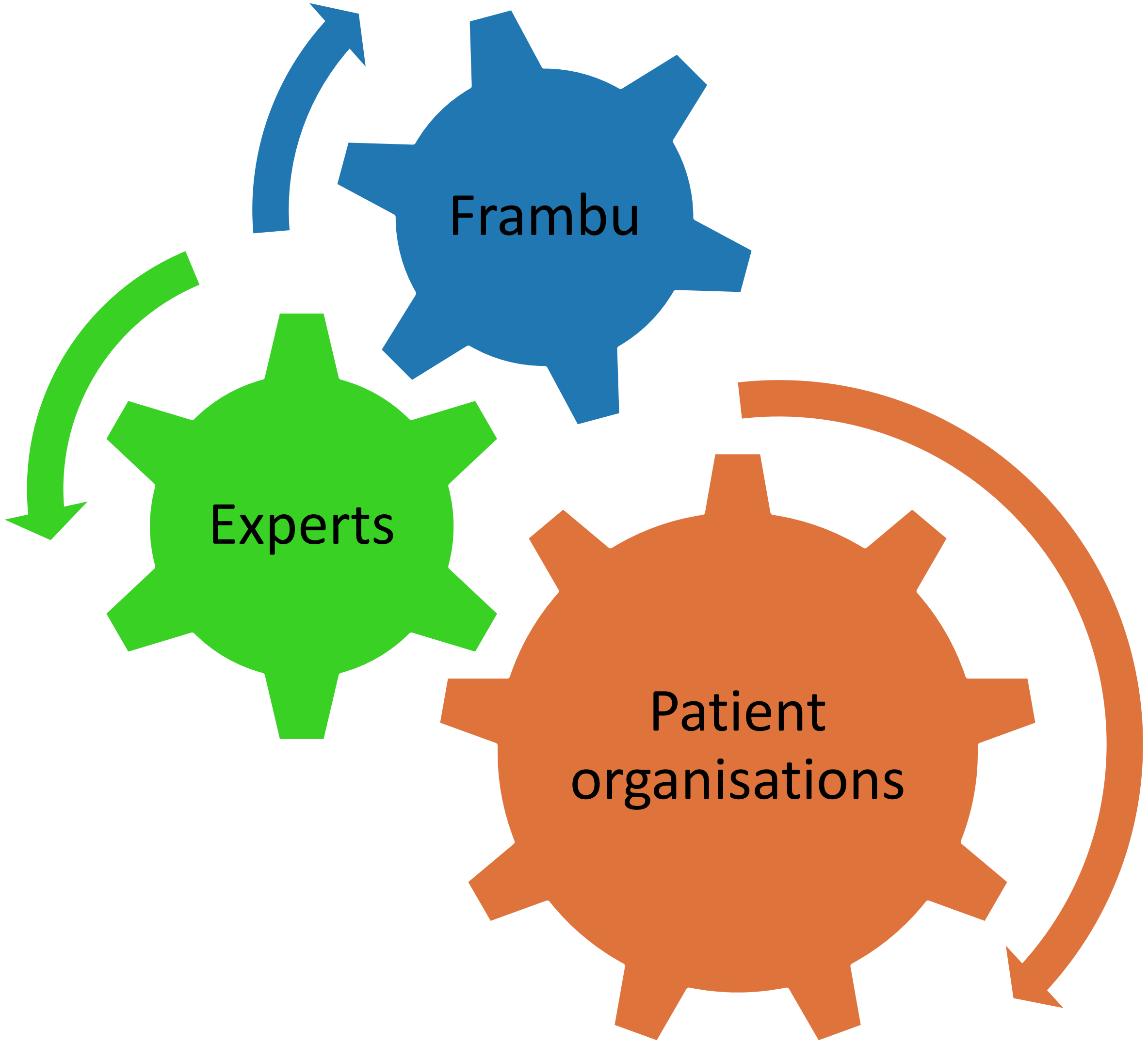
- Privat foundation and part of Norway’s specialist health care system
- Norway’s largest resource centre for rare disorders
- Interdisciplinary services in a life course perspective



The Frambu model



Frambu

Experts

Patient organisations

Research

Family courses

Courses for professionals

Counselling

European reference networks

Frambu in European reference networks

ERN EURO-NMD

ERN-ITHACA

MetabERN

Parents’ struggles and how to support them

Torun M. Vatne

MA Clin Psyc Phd

Frambu

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Being the parent of a child with a rare disorder

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Stress

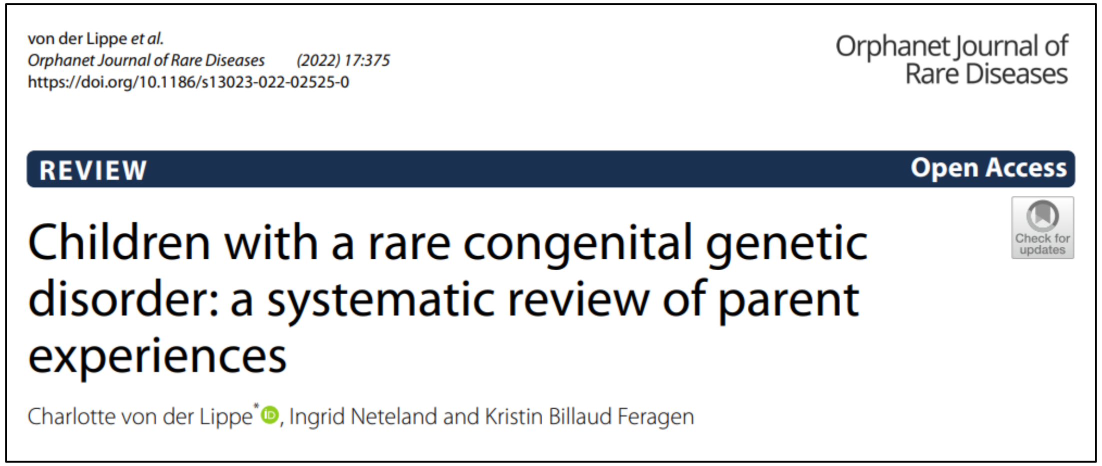
Long and complex diagnotic processes

Service providers lack of knowledge and expereince

Lack of koordiantion of the services

Feels responsible for information and coordination!

Are encouraged by engaged and supportive service providers that achnowledge parent experience!



von der Lippe *et al.*
Orphanet Journal of Rare Diseases (2022) 17:375
https://doi.org/10.1186/s13023-022-02525-0

Orphanet Journal of Rare Diseases

REVIEW **Open Access**

Children with a rare congenital genetic disorder: a systematic review of parent experiences

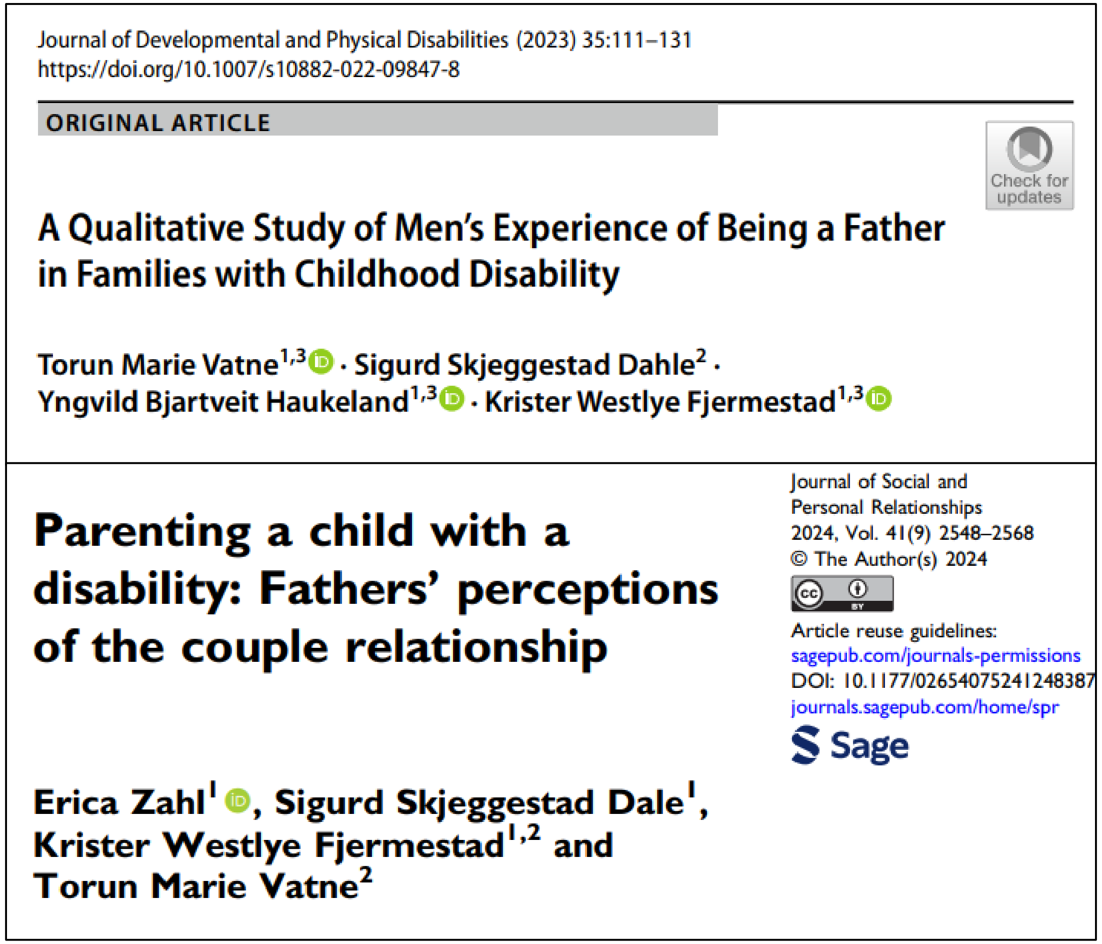
Charlotte von der Lippe*, Ingrid Neteland and Kristin Billaud Feragen

Roles and partnership

A more traditional pattern

Support system designed for women

Emotional communication affected



Journal of Developmental and Physical Disabilities (2023) 35:111–131
https://doi.org/10.1007/s10882-022-09847-8

ORIGINAL ARTICLE

A Qualitative Study of Men's Experience of Being a Father in Families with Childhood Disability

Torun Marie Vatne[1,3] · Sigurd Skjeggestad Dahle[2] ·
Yngvild Bjartveit Haukeland[1,3] · Krister Westlye Fjermestad[1,3]

Parenting a child with a disability: Fathers' perceptions of the couple relationship

Journal of Social and Personal Relationships
2024, Vol. 41(9) 2548–2568

DOI: 10.1177/02654075241248387
journals.sagepub.com/home/spr
Sage

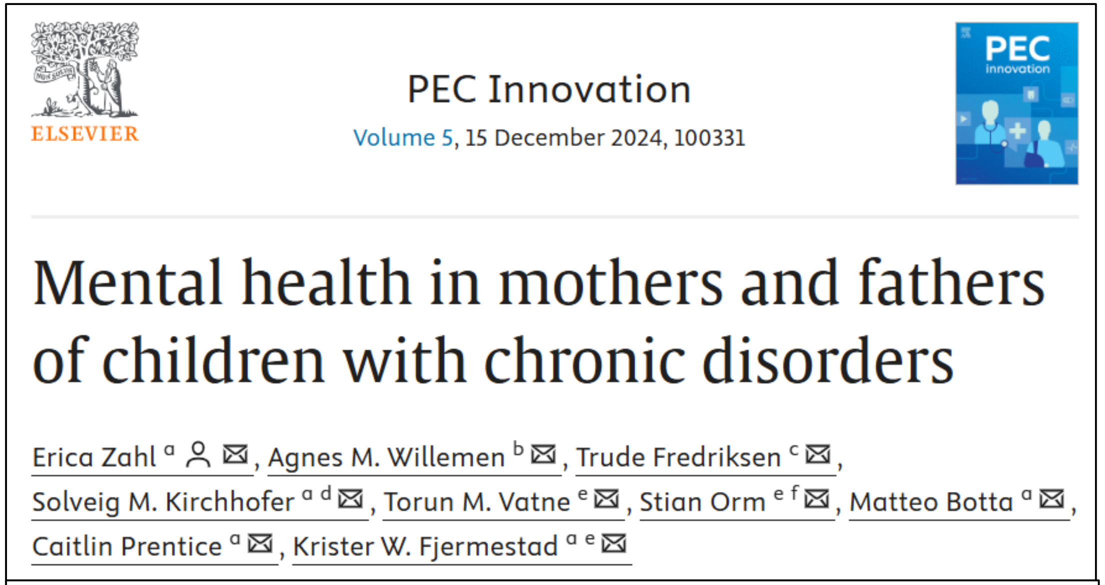
Erica Zahl[1], Sigurd Skjeggestad Dale[1],
Krister Westlye Fjermestad[1,2] and
Torun Marie Vatne[2]

Psychological challenges

Impact on parental mental health

Perceived disorder severity is an important factor

Findings suggest gender-specific challenges in parenting children with CD



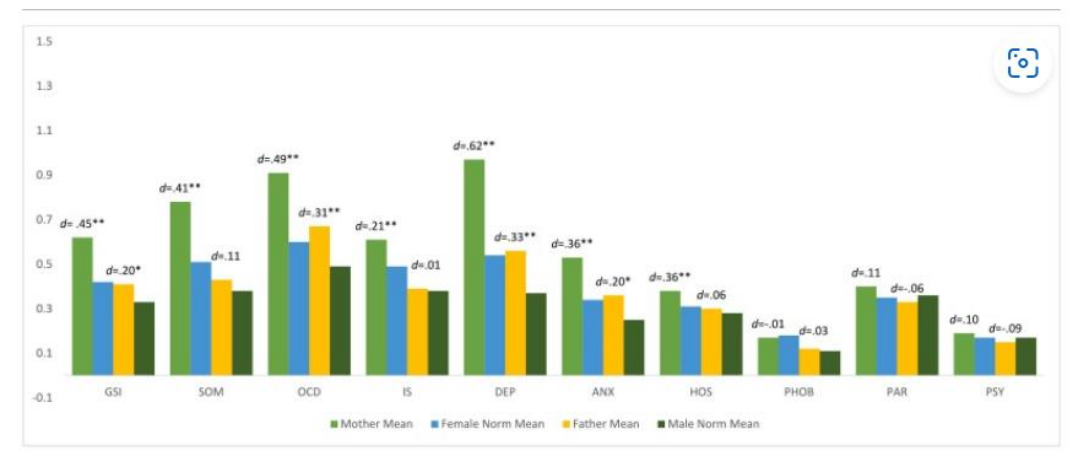
ELSEVIER

PEC Innovation

Volume 5, 15 December 2024, 100331

Mental health in mothers and fathers of children with chronic disorders

Erica Zahl[a], Agnes M. Willemen[b], Trude Fredriksen[c], Solveig M. Kirchhofer[a d], Torun M. Vatne[e], Stian Orm[e f], Matteo Botta[a], Caitlin Prentice[a], Krister W. Fjermestad[a e]



Health litteracy

Lack of knowledge and access to information about diagnosis, health, coping, support and rights

Important with information from healthcare personnel

Significant to get social support from likeminded

Stenberg *et al. Orphanet Journal of Rare Diseases* (2024) 19:328
https://doi.org/10.1186/s13023-024-03332-5

Orphanet Journal of Rare Diseases

REVIEW **Open Access**

A scoping review of health literacy in rare disorders: key issues and research directions

Una Stenberg[1,2*], Lydia Westfal[1], Andreas Dybesland Rosenberger[3], Kristin Ørstavik[4], Maria Flink[5], Heidi Holmen[6], Silje Systad[7], Karl Fredrik Westermann[2] and Gry Velvin[8]

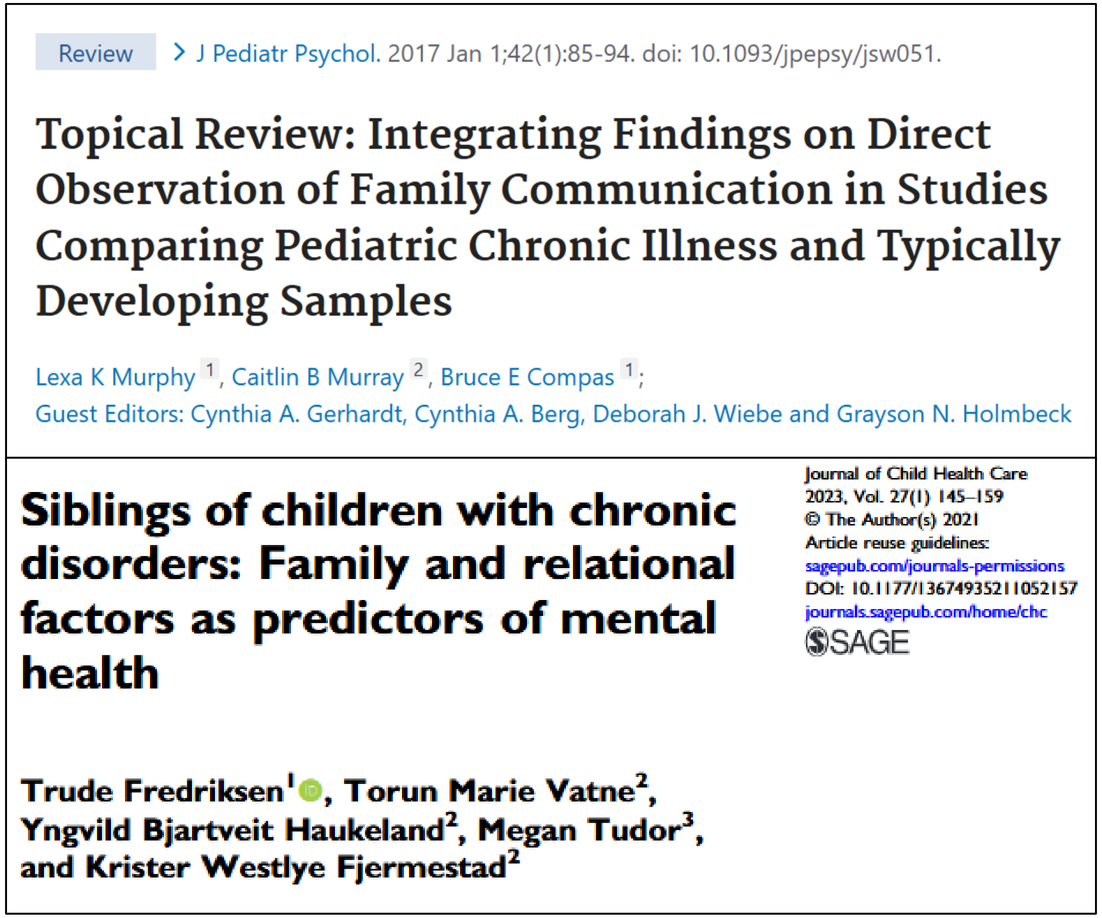
Family communication

Complex dilemmas about what to tell the children

Being promized but lacking support

Less warmth and more hostile communication

Communication and relation affect mental health of siblings



Review > J Pediatr Psychol. 2017 Jan 1;42(1):85-94. doi: 10.1093/jpepsy/jsw051.

Topical Review: Integrating Findings on Direct Observation of Family Communication in Studies Comparing Pediatric Chronic Illness and Typically Developing Samples

Lexa K Murphy [1], Caitlin B Murray [2], Bruce E Compas [1];
Guest Editors: Cynthia A. Gerhardt, Cynthia A. Berg, Deborah J. Wiebe and Grayson N. Holmbeck

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Journal of Child Health Care
2023, Vol. 27(1) 145–159
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DOI: 10.1177/13674935211052157
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SAGE

Siblings of children with chronic disorders: Family and relational factors as predictors of mental health

Trude Fredriksen[1], Torun Marie Vatne[2], Yngvild Bjartveit Haukeland[2], Megan Tudor[3], and Krister Westlye Fjermestad[2]

Support offered

«Parents on guard» - a on day course

Psychoeducation

Interventions
- Psychological
- Physical
- Social

Group discussions with likeminded

Information about available support

FRAMBU kompetansesenter for sjeldne diagnoser

Frambu > Kurskalender > Foreldre på vakt (regionalt kurs for Helse Midt-Norge)

Foreldre på vakt (regionalt kurs for Helse Midt-Norge)

System counselling with parents present

About rare disorders, for *m*=10 service providers and parents

Increased knowledge

Increased health litteracy

Increased empowerment

ORIGINALARTIKKEL FAGFELLEVURDERT

OPEN ACCESS https://doi.org/10.52734/AQDI3055

Foreldres diagnosekunnskap, helsekompetanse og myndighet før og etter veiledning om sjeldne diagnoser

Torun M. Vatne, Jeanette U. Miller, Mina Susanne Weedon-Fekjær, Una Stenberg

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Webinars/lectures on cooperation with partents

To increase understanding of parents situation

To increase knowledge on how to provide services in a sensitive way

To increase knowledge about ways to respond in emotionally charged situation

References

Fredriksen, T., M.Vatne, T., Bjartveit Haukeland, Y., Tudor, M., & Fjermestad, K. W. (2023). Siblings of children with chronic disorders: Family and relational factors as predictors of mental health. *Journal of Child Health Care*, *27*(1), 145-159.

Stenberg, U., Westfal, L., Dybesland Rosenberger, A., Ørstavik, K., Flink, M., Holmen, H., ... & Velvin, G. (2024). A scoping review of health literacy in rare disorders: key issues and research directions. *Orphanet Journal of Rare Diseases*, *19*(1), 328.

Vatne, T. M., Dahle, S. S., Haukeland, Y. B., & Fjermestad, K. W. (2023). A qualitative study of Men's experience of being a father in families with childhood disability. *Journal of Developmental and Physical Disabilities*, *35*(1), 111-131.

Vatne, T. M., Miller, J. U., Weedon-Fekjær, M. S., & Stenberg, U. Foreldres diagnosekunnskap, helsekompetanse og myndighet før og etter veiledning om sjeldne diagnoser. Psykologtidsskriftet.

von der Lippe, C., Neteland, I., & Feragen, K. B. (2022). Children with a rare congenital genetic disorder: a systematic review of parent experiences. *Orphanet Journal of Rare Diseases*, *17*(1), 375.

Zahl, E., Willemen, A. M., Fredriksen, T., Kirchhofer, S. M., Vatne, T. M., Orm, S., ... & Fjermestad, K. W. (2024). Mental health in mothers and fathers of children with chronic disorders. *PEC innovation*, *5*, 100331.

Zahl, E., Dale, S. S., Fjermestad, K. W., & Vatne, T. M. (2024). Parenting a child with a disability: Fathers' perceptions of the couple relationship. *Journal of Social and Personal Relationships*, *41*(9), 2548-2568.

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Helping patients with rare or low-prevalence complex diseases

Grandparents – and caring for the caregivers

Tonje Elgsås

MA Clin Psyc

Frambu

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How do we work with grandparents?

- Grandparents are invited to join the family on our week long family courses.
- Every other year we have a three day course for grandparents.
- Information on our website.
- Webinar.

FRAMBU kompetansesenter for sjeldne diagnoser

Frambu > Tema > Besteforeldre – de gode hjelperne?

Besteforeldre – de gode hjelperne?

Grief

- Many grandparents describe a grief related to loss of the grandparent role they had imagined.
- Grief is no longer reserved for the bereaved.
- Grief is a natural reaction to loss- can be related to loss of a partner, job.

«Double grief»

- Grandparents perceived their grief as double- both for their grandchild AND for their own children.

- They have to witness the distress of their child and grandchild.

Kongste, 2022

Societal expectations

- There exists an informal grief hierarchy, where grandparents grief is perceived less important than the parents grief.
- They are expected to «get over it» faster then the parents

Kongste, 2022

A topic that makes others uncomfortable

- Grandparents feel that children who are sick or have a disability makes other people uncomfortable.

→ They distance themselves from others, or dont bring the topic up.

Consequences

- Grandparents have to deal with two things: both their grief, but also societys reactions.
- Grandparents feel that they need to hide their grief from others.

→ Avoids social occasions, reacts more in private.

→ Feelings of being alone with their reactions.

→ Can for some lead to *delayed* reactions (which can be difficult for those around to understand).

Kongste, 2022

Why focus on grandparents?

- Grandparents are described as an enormous resource for the families.
- They can also be a resource for carers, with their help and also knowledge of the family.
- Next of kin are taking on responsibilities that in Norway is estimated to be akin to 140 000 full time positions (with a population of 5,5 million people).

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Caring for the carers

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Why is it important?

- It can be emotionally challenging work- either with behaviour that challenges, mental illness and/or complex medical care.

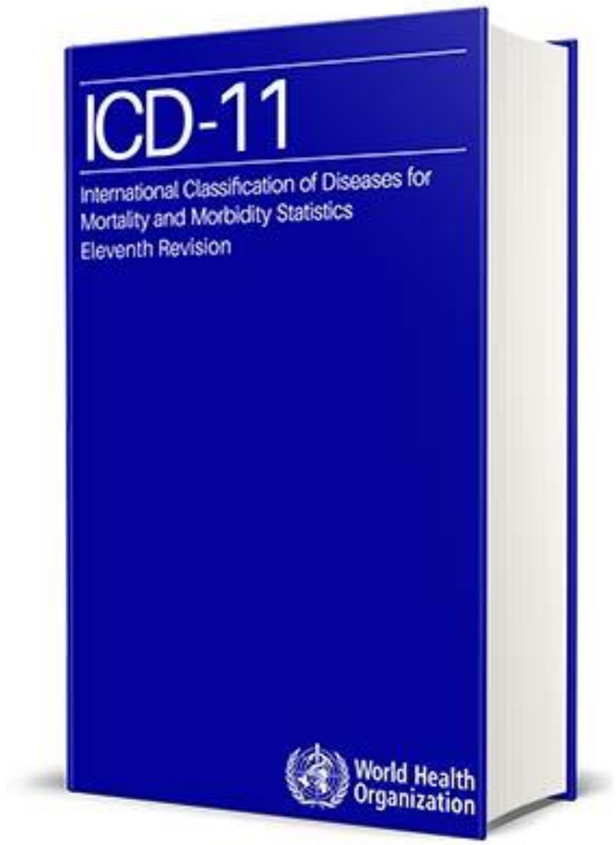
- The child/adult may need life long care and some also have difficulties communicating their needs.

→ Need stabile caregivers who knows them and their needs.

Why is it important?

- With rare diseases the carers doesnt have alot of research, litterature and experience to help guide them.

- Carers manage well in a high pace, demanding workplace <u>as long as they feel competent to do the tasks at hand.</u>



Burn out

A syndrome conceptualized as resulting from chronic workplace stress that has not been successfully managed. It is characterized by three dimensions:

- feelings of energy depletion or exhaustion;
- increased mental distance from one’s job, or feelings of negativism or cynicism related to one's job
- reduced professional efficacy

Caring for the carers

- Investing time and effort in caring for the carers is great for everyone!

→For the carer

→For the families

→For the workplace

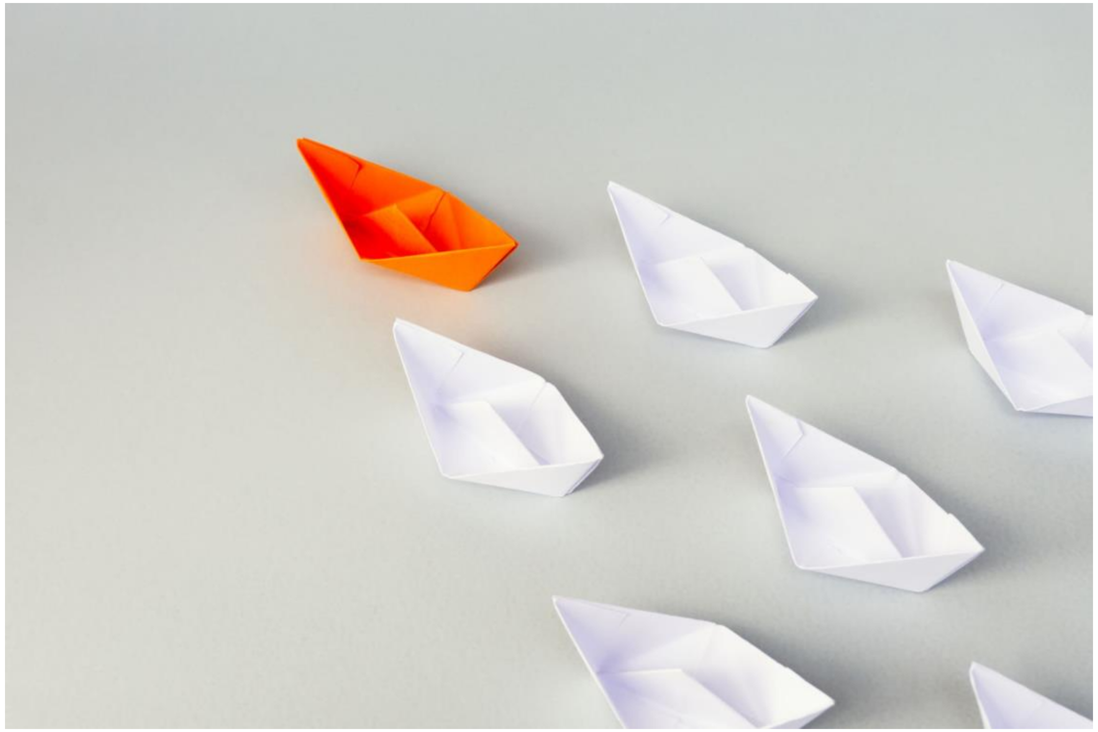
Burn out

- Many who have experienced work place related burn out describe being blindsided by the symptoms.

→ Carers need outside support to help see their symptoms.

- Research into preventing burn out show that the best is to intervene at an **organizational level** and that interventions directed at the individual have lesser effect.

→ The workplace needs to work systematically with burn out prevention.



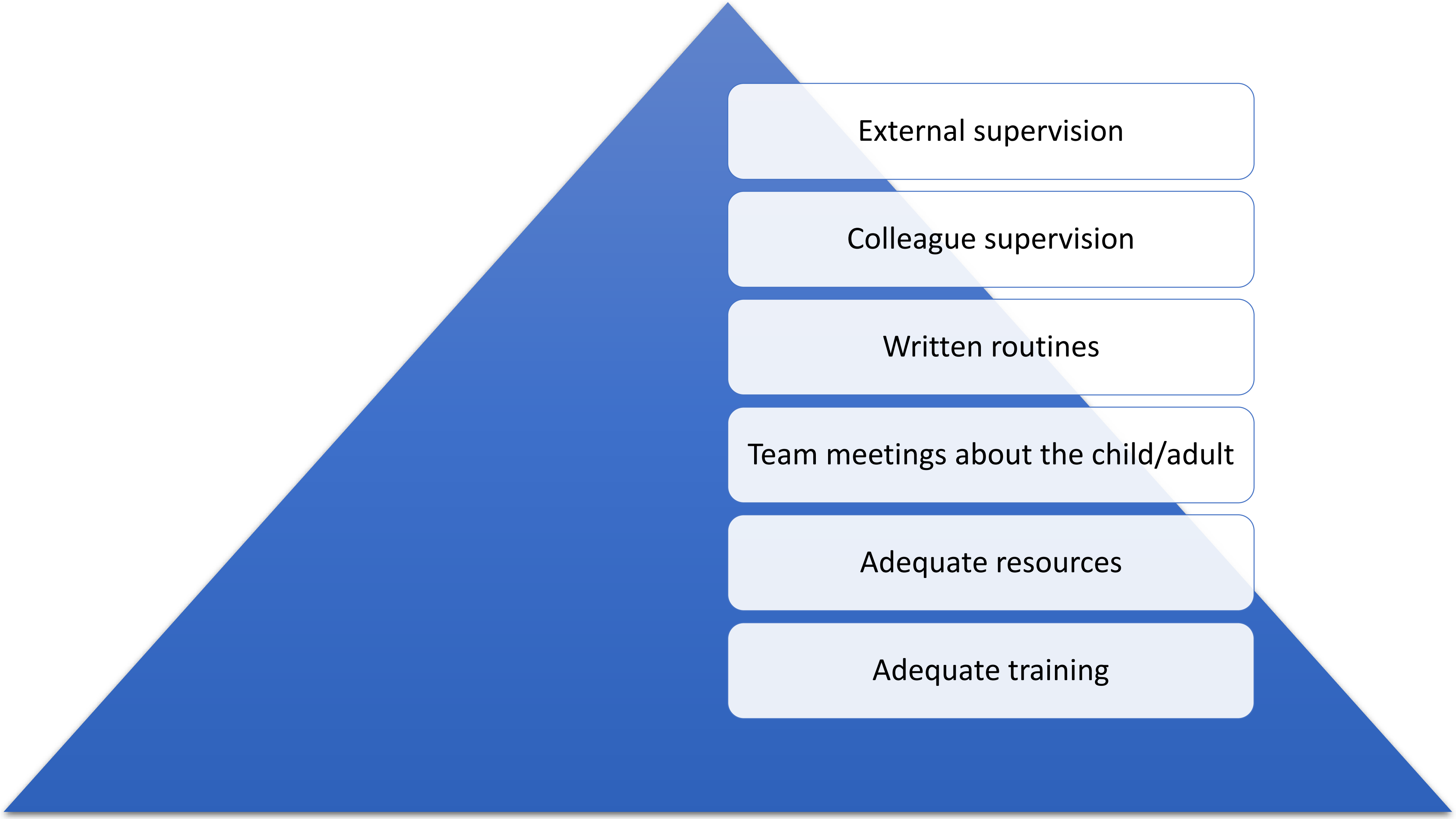
The 3 focus areas

- Self care
- Colleague support
- Management lead process

Workplace culture

- Working with culture and attitudes towards work related burn out.
- Focusing more on openness and supporting each other in the work place.

The basics of caring for the carers



- External supervision
- Colleague supervision
- Written routines
- Team meetings about the child/adult
- Adequate resources
- Adequate training

Thank you for your attention

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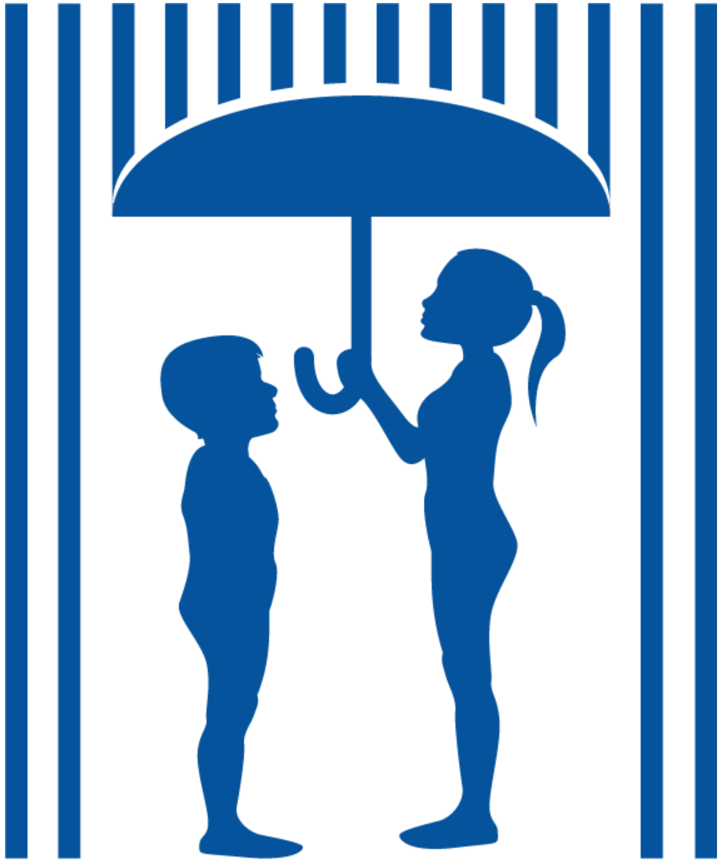


Siblings

Krister W Fjermestad

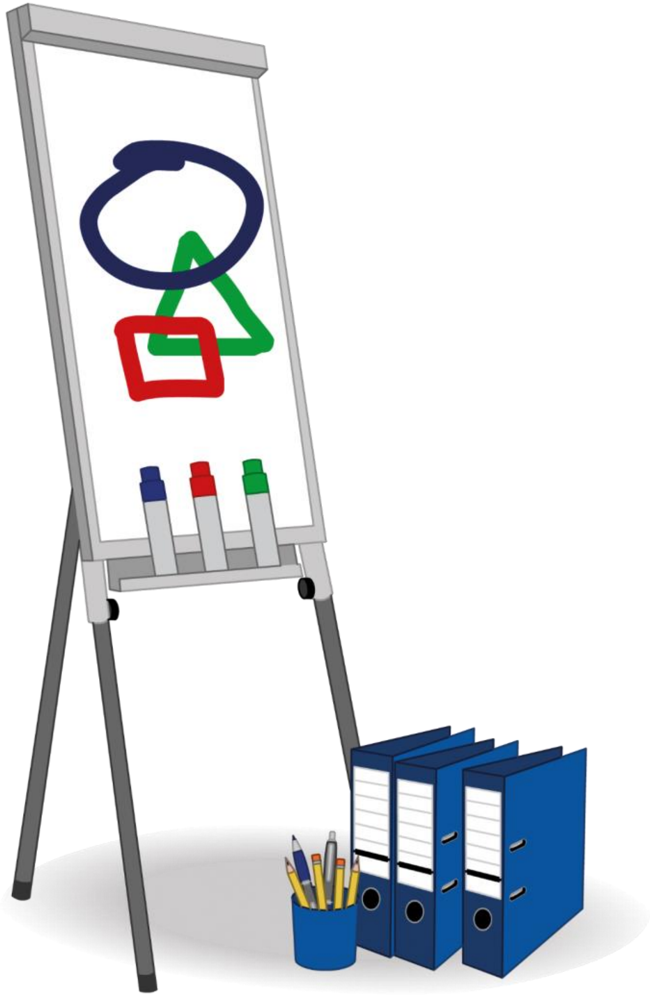
Doctor of Psychology

Frambu Resource Centre for Rare Disorders, Norway

2025

Outline sibling section

- Sibling risks
- Development of the SIBS intervention
- The SIBS intervention
- Pathways ahead



Sibling risks

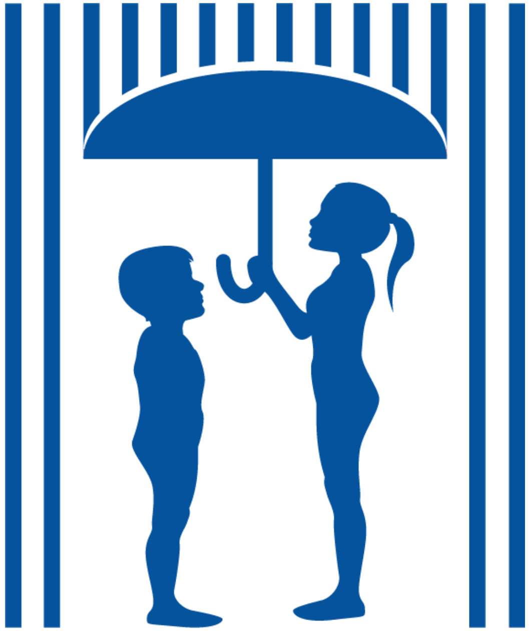
General

Chronic disorders

Rare disorders

Timeline for the development of SIBS

- Qualitative studies (2012-15)
- Manual development (2013)
- Open trial (2014-2017)
- Develop group leader training (2018)
- Randomized controlled trial (2019-2025)
- SIBS online (2020-)
- Implementation (ongoing)



The SIBS manual

SIBS

Manu

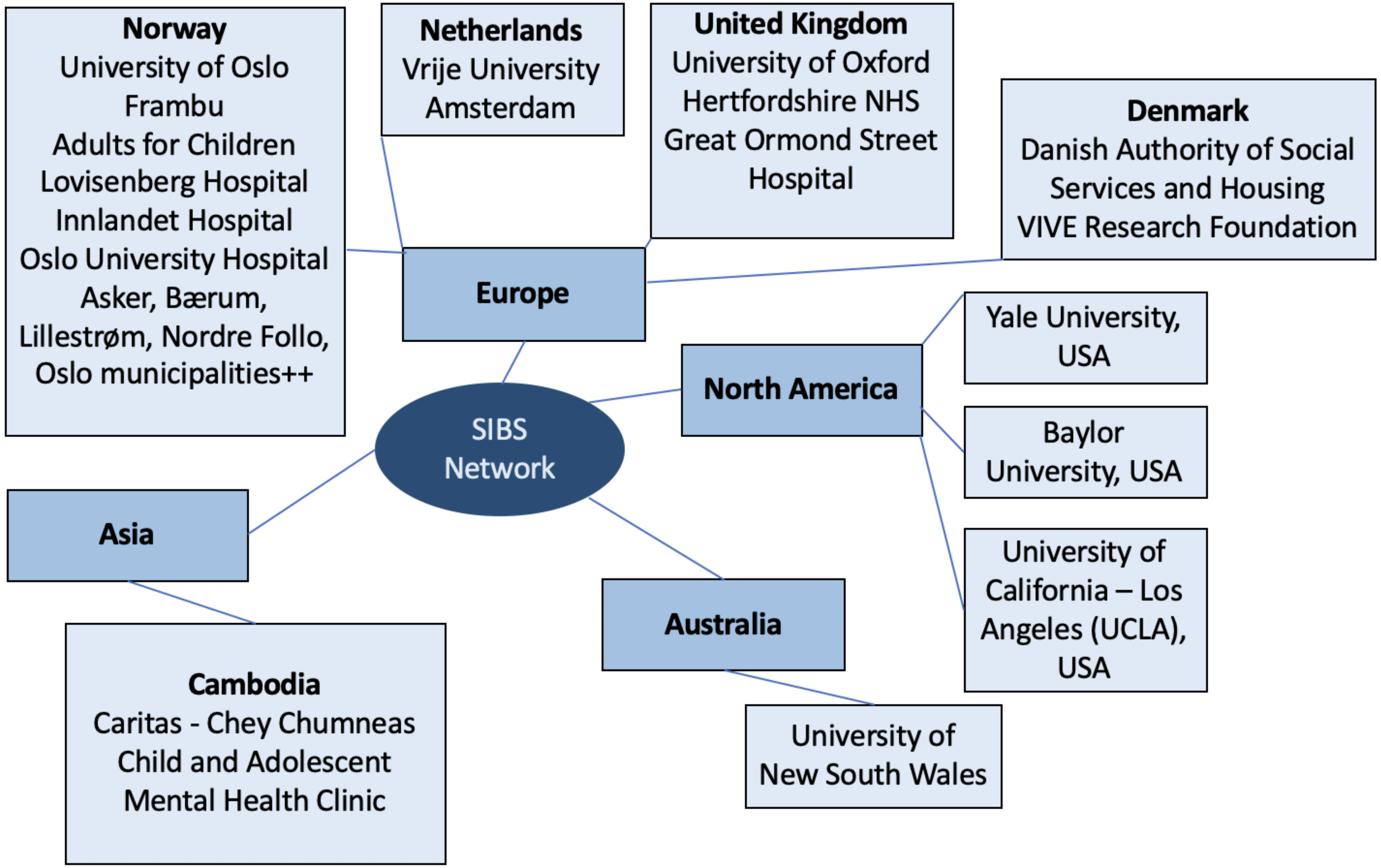
grupp

Torun M. Vat
Yngvild B. H

The SIBS intervention

	1. 20 min	2. 60 min	3. 60 min	4. 60 min	5. 60 min
Siblings	Intro	Disorder	Joint about disorder	Emotions	Joint about emotions
Parents	Intro	Disorder		Emotions	

Pathways ahead



SIBS Network

Europe

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Frambu
Adults for Children
Lovisenberg Hospital
Innlandet Hospital
Oslo University Hospital
Asker, Bærum,
Lillestrøm, Nordre Follo,
Oslo municipalities++

Netherlands
Vrije University
Amsterdam

United Kingdom
University of Oxford
Hertfordshire NHS
Great Ormond Street
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Cambodia
Caritas - Chey Chumneas
Child and Adolescent
Mental Health Clinic

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Thank you!

Discussion time - Conclusion with speakers and moderator

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Discussion & Conclusion

- Time for questions

- Satisfaction Survey :

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- Website :
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Thank you for your participation

ERN ITHACA Satisfaction Survey
Webinar April 8, 2025