

# Introducing the new Special Interest Group on *Family Engagement*

Chairs: Sara Rowaert & Ellen Tingleff

Webinar April 23, 2024



## Chairs of the SIG on Family Engagement



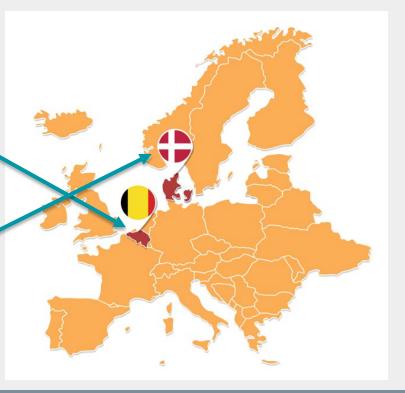
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- 2. Motivations and historical background of family research in forensic mental healthcare settings
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- 5. Starting a dialogue and sharing reflections



# Introducing the SIG on Family Engagement



## "To you he is a monster, to me he was a very sick boy" "I am just devastated - I love my son"



https://www.youtube.com/watch?v=BYGXPvBm0hw



## **Family Engagement?**

"Family engagement" refers to the **involvement of family members** in the care, treatment, and in the support of individuals experiencing mental health challenges.

Support and involvement can take various forms (Dirik et al., 2017; Ewertzon & Hanson, 2019):

- Support towards family members for their perceived burdens and needs
- Involvement of family members = how they are engaged in the care and treatment process
  (e.g., including participation in treatment planning/shared decision making, providing emotional
  support, and advocating for their loved one within the healthcare system).



## The story of the origin of the SIG

### Past IAFMHS conferences in search of:

- Family perspective and experiences
- Family interventions in forensic psychiatric care

### IAFMHS conference of 2022 in Berlin

Session with a specific focus on family experiences and interventions



## Start of an international group of researchers and practitioners

- Share a similar interest in family engagement initiatives
- Idea emerged to start a special interest group on the topic



## Our mission...

To bring together a group of (family) peers, practitioners and academics to build a foundation for research, training, education and the exchange of knowledge on family engagement (i.e., inform, consult, involve, collaborate, support and empower).



## ... how to achieve this?

- To establish a framework for research, training, education, support and information exchange
- To promote an international dialogue about family engagement
- To promote development/adjustment, testing, evaluation and implementation of (new) family interventions
- To impact the quality of care and treatment of the service user and family
- To impact science and support and create membership, leadership and research opportunities
- To produce practice guidelines for members and promote education and training on family engagement.



# Motivations and historical background of family research in forensic mental healthcare settings



## Motivations for fostering family engagement in mental healthcare

The importance of involving family members or considering family members as key stakeholders in a service user's mental health care has long been recognized (World Health Organization, 2001).

Family involvement is associated with a **better treatment outcome** in terms of medicine adherence, relapse prevention and reduced length of hospitalization (Ashcroft et al., 2018; Ong et al., 2021; Svendsen et al., 2021)

Government policy across countries supports the involvement and support of family members in mental health care. One key example is the NICE schizophrenia guidelines in the UK (2014).



# A historical background on family members of service users

Caregiver burden (Treudley 1946, Hoenig & Hamilton 1966)

Objective burden and subjective burden

**Stigmatization** (Goffman 1963, 2009)

Courtesy stigma and Self-stigma

## Resilience / family resilience

Resilience characteristics (Zauszniewski et al., 2010)

**Expressed Emotion** (Brown 1966, 1985)

Hostility, emotional overinvolvement, critical comments, warmth and positive regard



# Experiences of family members in forensic mental healthcare

Research about carers' experiences, burdens and needs has attracted less attention, compared to general mental healthcare (Sampson et al., 2019).

It has, however, been suggested, that carers of forensic service users face raised levels of burdens (Rowaert et al., 2016).



"It's still our child". A qualitative interview s forensic mental health

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REVIEW ARTICLE

Experiences of family caregivers care—A qualitative evidence syn

Tina Kirstine Vestphal<sup>1,2</sup> | Frederik Alkier Gi Sara Rowaert<sup>5</sup> | Ellen Boldrup Tingleff<sup>1,2,6</sup> ISSUES IN MENTAL HEALTH NURSING https://doi.org/10.1080/01612840.2024.2308544



Check for updates

Tilting at Windmills – A Qualitative Study about Family Caregiver Interactions and Perceptions in Forensic Mental Health Care

Tina Kirstine Vestphal, PhD student, MScN, RN<sup>a,b</sup> (i), Ellen Boldrup Tingleff, PhD, MScN, RN<sup>a,b</sup>, Rikke Jørgensen, PhD, MScN, RN<sup>a,d</sup>, Sara Rowaert, PhD, MEd<sup>e</sup> and Frederik Alkier Gildberg, PhD, MScN, RN<sup>a,b</sup>

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## **Examples of family interventions in forensic mental** healthcare

Few interventions to support and involve family members have been developed or adapted to the forensic mental health care setting (Sampson et al. 2019)

Journal of Forensic Psychology Practice, 15:171-183, 2015 Copyright 40 Taylor & Francis Group, LLC ISSN: 1522-8932 print/1522-9092 online DOI: 10.1080/15228932.2015.1013786

Bridging the Gap: Brief Fami Psychoeducation in Forensic Menta

CLAIRE NAGI, DForenPsy, and JASON DAVIES, Abertawe Bro Morgannung University Health Board, Bridgen and Department of Applied Psychology, School of Health Sc Cardiff Metropolitan University, Cardiff, Wales

**Australian & New Zealand Journal of Family Therapy** 



A Family Support Group for Family Members of Offenders with a Mental Illness - Part 2: Treatment Protocol

Sara Rowaert (D), Femke Hanssens, Kurt Audenaert, Stijn Vandevelde, and Gilbert Lemmens Ghent University, Ghent







## Struggles of providing family engagement

## Family members experience barriers, such as (Rowaert et al., 2022; Tingleff et al., 2022; Vestphal et al., 2023):

- Geographical distance between the forensic unit and the family home
- The secure environment and restrictive procedures (limitations on visits or restricted visiting hours)
- o Particular challenges faced by family members of forensic service users, e.g. struggles with the legal proceedings, violence within the family, experiences of dual stigmatization etc.

## Professionals experience barriers, such as (Hörberg et al., 2015; Richards et al., 2009; Riebschleger, 2005):

- Lack of time, skills and resources
- Medical confidentiality limits to give information
- Perceive family members as unreasonable and difficult to work with



## Research trajectories



## Topics of the research initiated and upcoming

- 1. Service users' experiences on and wishes for family engagement
- 2. Family experts-by-experience
- 3. Professional perspectives on collaboration with family members
- 4. Family interventions



## Service users' experiences on and wishes for family engagement

## **Ongoing study:**

A qualitative systematic review and thematic synthesis (Tingleff, Rowaert, Davies and Pedersen)

12 studies included, none of these within forensics

## **Future study:**

**Qualitative, in depth interviews with forensic service users** (Aslerin, Rowaert, Jørgensen, Tingleff) **Aim**: What characterizes the wishes and perceptions held by service users in forensic settings regarding involvement of their family members in care and treatment, including perceived dilemmas regarding informed consent.



## Family experts by experience

Only recently more attention is given to include family experts by experience (together with service user expertise) in forensic mental healthcare.

## **Ongoing study:**

Scoping review on (family) lived experiences in forensic mental healthcare (research collaboration: UGent, PC Sint-Jan Baptist and family organisations in Belgium).

Development of a guide to implement experts by experience (both service user and family members) in forensic mental healthcare (research collaboration: UGent, PC Sint-Jan Baptist and family organisations in Belgium).

#### Ideas for future research:

- good practices?
- ...



## Professional perspectives on collaboration with family members

## **Ongoing studies:**

A qualitative research study: Transitioning from Passive to Proactive Family Involvement in Forensic Psychiatric Care throughout the years (Rowaert, Tingleff, Hörberg, Vandevelde & Lemmens) 23 forensic mental healthcare professionals (FMHP) included: 2 focus group interviews in 2015 (n = 11 participants) and 12 individual interviews in 2021.

Survey study on family involvement in forensic mental healthcare

**Aim**: we want to learn more about how family members are and can be involved in forensic mental healthcare



## **Family interventions**

## **Future study:**

The FSI forensic project: Family Support and Involvement in forensic mental health settings. (Tingleff, Rowaert, Jørgensen og Hansen).

Aim: To adapt, test and evaluate targeted interventions aiming to provide support and facilitate involvement of family members in forensic mental health settings based on research-based knowledge.

WP 1: Development of knowledge (survey, review and interviews)

WP 2: Adaptation, test and evaluation of interventions (survey, design, test and evaluation of interventions)

## **Ongoing study:**

Family support groups in forensic mental healthcare inpatient settings (Rowaert and colleagues)



## Stay tuned!



## Stay turned for the upcoming conference in San Francisco

SIG group meeting: Discussion around topics of research

- Service users' experiences on and wishes for family engagement
- Family experts by experience
- Professional perspectives on collaboration with family members
- Family interventions

**Symposium**: "Support and involvement of family members in forensic mental health settings: Evolutions through the years".

Several oral presentations and poster presentations related to family engagement



Starting a dialogue & sharing reflections



## A question we have for our audience

## What does family engagement means for you?

How are you working towards family engagement in research/your organisation/...?

What ideas/plans for family engagement initiatives in research/your organisation/... do you have?





## Reflections and thoughts

- Do you have questions for us?
- What are your reflections on the presentation?
- Do you have ideas/suggestions for coming SIG-meetings?



## Let's connect:

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