

Second FAMILY Stakeholder Dialogue Event

A Dialogue on Stigma: Research, Reality, and Response

The 2nd [FAMILY](#) Stakeholder Dialogue Event was held online on 10 June 2025, bringing together 38 participants from across Europe. Organised in collaboration with the [Re-MEND](#) and [R2D2-MH](#) projects, the event focused on the current perceptions of stigma surrounding mental health. The stakeholder event combined academic perspectives with insights from individuals with lived experience. The three-hour programme featured expert talks and interactive discussions that explored how stigma manifests today, what current research reveals, and which practical responses are needed in both scientific and everyday contexts.







Program summary

The event opened with a welcome from FAMILY coordinator Neeltje van Haren, setting the tone for an open and inclusive dialogue. The first session, held and moderated by Andrea Raballo, addressed the role of stigma in mental health care, particularly its impact on mental health professionals. This was followed by a powerful conversation with individuals with lived experience, who shared how they experienced stigma in their lives, and how they responded to it. Kaylee van Tilburg (LUMC Curium), André Decraene (EUFAMI), and Cecil Prins-Aardema (child and adolescent psychiatrist, researcher, and professional with lived experience at GGZ Drenthe Family Psychiatry) contributed their personal perspectives. This insightful exchange was followed by a presentation from Re-MEND researchers Angelika Augustine and Doreen Reifegerste, who explored how responsibility framing and emotional

responses shape public perceptions of people living with depression. They highlighted the consequences of mental illness stigma and the role of news reporting in reinforcing or reducing it. Their talk also explored how different responsibility frames influence attitudes toward mental health, and whether mental illness is caused by genetic or biological factors, environmental or lifestyle factors, or a combination of both. Next, Julie Segers, Cecilia Ingard, Chantel Fouche, and other members of the neurodivergent co-creation groups from the R2D2-MH project shared their experiences with inclusive research practices and the shift from treating neurodivergent people as passive subjects to recognising them as active collaborators. In the first part of their presentation, they introduced their [language guide](#), developed specifically for neurodiversity research. The guide supports researchers in critically reflecting on their language when writing scientific texts, encouraging terminology that is both scientifically sound and respectful. Rather than policing language, the guide invites researchers to communicate with intention and care, ensuring that their work supports and respects neurodivergent individuals. In the second part of the R2D2-MH session, participants were actively involved in small-group discussions. They explored three guiding questions focused on language and communication in the context of stigma. The event closed with a brief final discussion and concluding remarks by Neeltje van Haren, highlighting the need for cross-sector dialogue to address stigma on both systemic and personal levels. Due to time constraints, the discussion had to be cut short. However, to ensure that participants can continue the exchange, a follow-up meeting is planned for all those interested.

Useful Resources:

Project		Resource
	FAMILY	Website: https://family-project.eu/
	Re-MEND	Website: https://www.helsinki.fi/en/projects/re-mend
	R2D2-MH	Website: https://www.r2d2-mh.eu/ Language guide for neurodiversity research
	EUFAMI	Website: https://www.eufami.org/en

Summary from group work on language and communication in the context of stigma

You may have a different way of communicating and/or processing information than the people with lived experience. Which barriers may arise? How could you overcome those barriers?

Main Barriers Identified:

1. Miscommunication and Misunderstanding

- Different communication styles between researchers and people with lived experience.
- Scientific or medical terminology can feel cold, distancing, or stigmatising.
- Emotional disconnection: academic language often lacks the emotional resonance of lived experience.
- Terms may carry unintended meaning or emotional weight for others (e.g. “social deficit”, “hallucination”, “overstimulation”).
- Lack of language equivalency when working in non-English contexts.

2. Lack of Awareness and Training

- Researchers may be unaware of how language choices can reinforce stigma.
- Different (scientific) fields use different language norms.
- Fear of unintentionally offending someone due to unfamiliarity with sensitive terminology.
- Limited training on how to communicate with people with lived experience respectfully and inclusively.

Suggestions to Overcome Barriers

1. Adapt Communication Practices

- Ask for preferences: Proactively ask collaborators how they prefer to communicate.
- Co-develop language: Work with individuals with lived experience to co-create shared terminology.
- Reflect on language: Encourage researchers to question their own word choices and framing.
- Be aware of change: What may be okay today, may be offensive in a few years.

2. Build Awareness and Skills

- Education is key: Make inclusive communication part of academic curricula and professional development.
- Educate yourself, as it is your responsibility to make sure you use the right language.
- Use reflective tools: For example, language guides to support respectful terminology.

- Find a “buddy”: Collaborate closely with someone with lived experience to get direct feedback

3. Create Dialogue

- Keep the conversation open: language evolves, and staying in touch with affected communities is essential.
- Encourage humility and willingness to learn from feedback, even when it's uncomfortable.
- Acknowledge that mistakes may happen and use them as learning moments.

4. Language Diversity Considerations

- If English is not your first language, make the effort to translate inclusive terms and discuss them in your local context.
- Foster national-level discussions to localise inclusive practices and terminology.

How do you think affirmative language could empower people with lived experiences?

- Affirmative language gives people with lived experiences a feeling of being truly understood.
- It affirms their humanity, helping them feel whole rather than “broken”.
- Positive and supportive language empowers individuals by fostering confidence and resilience.
- It helps them regain a sense of control over their situation.
- When healthcare providers offer positive, solution-oriented responses, it contributes to a more empowering and validating experience.
- In contrast, some healthcare professionals fail to listen seriously or dismiss concerns, which undermines empowerment.

Which channel do/could you use for communicating with people with lived experiences? What are pro's and cons of these channels?

1. Communication Methods and Channels

- Use participative methods throughout the [research] project to actively engage people with lived experiences.
- Common channels include meetings (online or in-person), emails, and short-format messages such as tweets.
- Phone calls may be more efficient than lengthy emails but personal preferences vary.

2. Audience Diversity and Preferences

- The best approach is to ask people directly about their preferred communication method.
Example: “I notice you don’t respond to emails; is there a better way to communicate?”
- Different individuals require different communication styles and channels.
- Direct, personalized communication is important to meet diverse needs.

3. Limitations of Certain Channels

- Scientific publications are generally not effective for communicating with people with lived experiences.
- Social media offers broad reach and accessibility but carries a high risk of misinterpretation.

4. Engagement Opportunities

- Schools and colleges can serve as venues for optional social meetings to foster community engagement.
- Group meetings, such as those in rare disease communities, provide valuable opportunities to bring people together.

Conclusion

The 2nd FAMILY Stakeholder Dialogue Event created a valuable platform for exchange on mental health stigma, combining academic research with lived experience. Key themes included the impact of stigma on care and perception, the influence of responsibility framing, and the importance of inclusive language in research. Participants discussed barriers to effective communication, the empowering role of affirmative language, and practical strategies to foster respectful dialogue. The event underscored the need for ongoing, inclusive collaboration - both in research and beyond - to challenge stigma at personal, professional, and systemic levels. A follow-up meeting is planned to continue this essential conversation.