

By Jolijn Santegoeds, *Expert by Lived Experience, Bachelor of Sustainable Engineering, Founder of Stichting Mind Rights, Co-Chair of the World Network of Users and Survivors of Psychiatry*

Respecting persons and dealing with diversity in psychosocial crisis situations **Experience-based development of an alternative to forced psychiatric interventions**

Is it possible to respect diversity and legal capacity when persons are perceived as imposing a danger or harm to self or others? Is it possible to take an alternative approach and not intervene by force? Is it possible to use an experience-centred approach in psychosocial crisis situations?

- Yes, it is.

In this article, I will describe the development of the “Eindhoven Model for supported decision making by using Family Group Conferencing in and to prevent psychosocial crisis situations”. This is an experience-based alternative model to avoid forced psychiatric interventions. It will show that experience-based knowledge can give new informed dimensions to advance respect for human rights in mental health care.

My own experiences and vision formed the basis for designing *The Eindhoven Model*, combined with my studies of *Sustainable Engineering*. In the next paragraphs I will describe the relevant personal experiences and vision behind the creation of the model, and then I will explain the *Eindhoven Model* and *Family Group Conferencing*, as an alternative to forced psychiatric interventions.

Based on my personal experiences

My own experiences in various situations formed the basis for designing the Eindhoven Model. I have horrible memories of being forcefully admitted in a psychiatric hospital from age 16 to 19. After that I was homeless, and I noticed that my personal freedom restored through homelessness, helped me to recover my wellbeing. In addition, my family setting also played a role: I grew up with a brother with Down syndrome, and also my mother had some challenging episodes in her life which I witnessed closely. I learned a lot from these experiences.

My experiences laid the basis for my vision on the matter, and led me to become an activist against forced treatment. When I was invited for consultation in the process of law reform on forced psychiatric treatments, I eventually made my own design of an alternative model for which I also reflected on my own experience-based knowledge. Certain experiences are the foundation for my actions and also for this development process of the Eindhoven Model. I will elaborate briefly on the main experiences which define my point of view.

Brief description of relevant personal experiences:

Communicating with my brother: A natural process of connecting to one another

Throughout my life, I communicate on a natural basis with my brother who has Down syndrome. Somehow I automatically know how to phrase something to make it understandable to him. And also for me, interpreting his way of doing comes intuitively. After all, we know each other very well. Communicating with my brother doesn't feel like a special effort to me. After all, communication is always personal: Everyone is unique, but we are all human beings.

Understanding my mother: Witnessing emotional pain and misunderstanding

As a child, I witnessed my mother being overwhelmed by coinciding events and many feelings. Despite the clear social origin of these overwhelming feelings, it was labelled as “a mental illness” (“psychosis”). It was a taboo. The silence on the topic wasn't helpful. I have seen my mother being dragged away by crisis services. She was crying and struggling from fear. It made me afraid as well. I know my mother is able to balance when she gets support. I have often helped her calming down successfully. There was no need to use force. The crisis care services should have taken a more careful approach instead of hurting my mother and traumatizing the entire family.

My own experiences: Forced treatment only made it worse

As an adolescent at age 16, I faced my own psychosocial problems. I thought I was ‘weird’ and I attempted suicide. I was involuntarily placed in a psychiatric institution where I was solitarily confined, forcefully drugged and subjected to restraints for almost 2 years continuously. This was done to prevent suicide, but it only made me more miserable and more suicidal. It was horrible. Although my self-destructive reaction was understandable, this was referred to as a severe mental illness; a so-called “Borderline personality disorder”. I never felt that this was appropriate. The repressive treatment was traumatizing and causing escalations. They should have paid attention to the social meaning of my behaviour. I just couldn’t live like that.

My recovery: I needed freedom to discover my identity and find my way

Luckily I was transferred to another ward, where I wasn’t locked up 24/7 anymore, and I felt no longer surrounded by ‘enemies’ who were hurting me, but by human people who wanted to support me in finding out how I could build up a life again. They were not perfect, but I developed new hope and stopped feeling suicidal. Then I left the institution and became homeless. To me this meant freedom to make my own choices and develop my own identity. I managed to find my own way and I have a satisfying life now. I clearly needed positive chances to recover.

Activism: Forced psychiatric treatments cannot be called care.

A core value in health care is: “*first do no harm*”. Despite this principle, I have been harmed by mental health care. It appears that many people have similar horrible experiences of a rigidly repressive mental health care system that doesn’t facilitate recovery, but traumatizes persons and neglects social meaning. The collectiveness of harm caused by psychiatry motivated me to become an activist against forced psychiatric interventions.

I am the founder of *Stichting Mind Rights*¹ and Co-Chair of the *World Network of Users and Survivors of Psychiatry*², and an active member of the *European Network of Users and Survivors of Psychiatry*³. I have seen the devastating impact of forced interventions in many forms and I have seen the power of social support and positive opportunities. Both good and bad experiences give a chance to learn.

Some relevant learning points from these experiences:

- Forced psychiatric treatments are not helpful but traumatizing.
- Every reaction has a cause, and there is meaning behind behaviour.
- All feelings are human feelings, and there is no mental illness, only social problems.
- People respond better to positive stimulation than to a negative approach. It is more important to look at what can be done, instead of what cannot be done.
- Life is dynamic, situations and emotions can change. Overcoming challenges and recovery from hard episodes is possible. Growth is part of life. Mental health is not static.
- Opportunities are needed to enable growth.
- Communication can create understanding, prevent problems, generate solutions, and is the key to peace and harmony.
- Any person is capable of communication, regardless of any kind or degree of disability. It is the approach that matters.

My personal experiences and perceptions have been of great influence during the development of the Eindhoven Model. Besides having personal experience-based expertise, I also have a Bachelor of *Sustainable Engineering*⁴, which gives me some useful skills for managing development projects.

¹ Actiegroep Tekeer tegen de isoleer! (2003)/ Stichting Mind Rights (2006): NGO/DPO against forced psychiatric treatments, www.mindrightrights.nl

² WNUSP: World Network of Users and Survivors of Psychiatry, www.wnusp.net

³ ENUSP: European Network of Users and Survivors of Psychiatry, www.enusp.org

⁴ Sustainable Engineering: Milieugerichte Materiaaltechnologie, Avans Hogeschool Tilburg (2001-2005)

The role of my experiences

For developing the Eindhoven Model, I used the knowledge originating from user experiences in several ways.

Experiences as a basis for understanding the matter

Personal experiences matter, especially in mental health care. All persons are human beings first, with human feelings and human reactions to situations; this is also the case when they find themselves in mental health care.

- The inner life of persons cannot be neglected. The label of 'mental illness' is devaluing and disrespects the human experience. It is not a medical problem at stake; it is mainly a social problem.
- Doing harm cannot be called: providing care. When an intervention is not helpful according to the user, it is not care.
- Without an accurate definition of the theme and an accurate analysis of the problem, it is generally impossible to find a good solution. My experiences provide a basis for redefining the theme within an experience-based view.

Experience as an indicator for development

Research and development in industrial or commercial settings is done by reviewing customers' experiences. The absence of complaints indicates quality. By analysing complaints, existing malfunctions can be addressed and resolved.

- Unfortunately, in mental health care we do not see a learning cycle built around user experiences. The many complaints about wrongdoings by mental health services indicate that there are huge shortcomings in the quality of these services, but the complaints are mainly repressed, and not used for improvements. This is a waste of very valuable expertise. From my experiences, I can tell what is experienced as problematic in the view of users, and in which directions improvements can be made.

The role of engineering skills

For developing the Eindhoven Model, I used a systematic approach, according to the general stages of product engineering. This means that I identified the following stages and steps of the design process:

- 1. Define: *Analysis and Predesign***
 - Identify the need or problem (idea generation)
 - Research the need or problem and identify criteria for the idea: package of key demands
 - Brainstorm on possible solutions : generate many ideas : explore possibilities (imagine)
- 2. Design: *Specification***
 - Find/select the best possible solution
 - Identify specific requirements
 - Refine the design
- 3. Develop: *Prototyping/test-phase***
 - Make it: prototyping, pilot project, mock-up
 - Test, evaluate and refine the design
- 4. Deliver: *Implementation and Maintenance***
 - Put the product on the market
 - Quality control (*linking back to defining stage*)

The Eindhoven Model is currently at the Development stage (pilot project). The next paragraphs correspond with the above engineering stages for developing the Eindhoven Model by defining a vision, a package of key demands, and finding a possible solution in *Family Group Conferencing*.

Opposing the law proposal on forced treatment - a mission since 2008

As an expert with lived experience, I was invited to the consultation process regarding the Dutch law reform on forced treatments in mental health care in 2008.⁵ I fully reviewed the draft law, and I found myself morally opposed to the suggested expansion of options for forced interventions. In relation to this law reform process, I wrote several articles and manifestos⁶ with reflections on every part of the law from my perspective, analysing the situation and backgrounds.

I used my experiences to define the real question. According to me, the real question is: *How to help persons who face a psychosocial crisis situation?* instead of: *When to start forced interventions?* (which is a horrible, illegitimate and unacceptable goal). I also used my experiences to define the existing shortcomings and complaints, in order to find a clear direction for improvement (a respectful, social and human approach). Clearly, a law about mental health care should be about providing care, and not about administration of forced interventions against the consent and will of the individual and which is considered as torture and other cruel inhuman or degrading treatment or punishment. The systematically wrong approach of crisis-situations by the official mechanisms caused me eventually to develop an alternative model (2009), based on using *Family Group Conferencing* for supported decision making in mental health crisis situations (called "*the Eindhoven Model*", also known as *Open Mind Support Meetings*).

Through the various manifestos and articles in reaction to the law reform process, I identified the problems and related dynamics, and defined an experience-based vision on the issue of dealing with psychosocial crisis situations.

Experience-based vision on mental health care

Mental health is about wellbeing. Mental health is about coping with life and feelings. Mental health is highly related to the social environment of a person. Unequal social, sexual, economic power relations are very strong factors in causing psychological and psychosocial problems. For example violence, power abuse, child abuse, sexual abuse, traumatising events, unemployment, absence of a family or social network, poverty, drug abuse, lack of opportunities etc. are all social circumstances which can lead to an outburst of psychosocial problems. Coping with these problems is a very personal process.

Across different cultures and different ages, there are a variety of ways of dealing with grief, loss, insecurity, anger etc. In all communities there are certain codes of conduct. (e.g. No shouting at nights etc.). In general, society defines the boundaries of acceptance and tolerance of this individual behaviour. A person with 'mental health problems' is generally in some way not complying with the preferred form of conduct and behaviour, which leads to a social problem. When this problem is linked to one's personal state of mind, it used to be called a "mental problem", and now it is called a psycho-social problem, manifesting on the cutting edge of a person's psychological state and the

⁵ Wet BOPZ: Dutch law on Special Admissions in Psychiatric Hospitals.

⁶ Manifestos with a vision on law reform by Jolijn Santegoeds, Stichting Mind Rights www.mindrights.nl :

- **Manifesto 1: Confinement is not care, care is compassion** (22 April 2008)
- **Manifesto 2: Right to Care – Prima Remedia instead of Ultimum Remedium** (18 May 2008)
- **Manifesto 3: Recycling of values - What is right in mental health care?** (16 June 2008)
- **The Eindhoven Model for supported decision-making - by using Family Group Conferencing in and to prevent crisis situations in the field of mental health** (28 January 2009)
- **Manifesto 4: Time for a transition policy for social innovation in mental health care** – discrepancy between the Dutch draft law on Mandatory Mental Health Care and the UN Convention on the Rights of Persons with Disabilities (16 April 2009)
- **Manifesto 5: Coercion is not a solution, but a problem! – Invest in care instead of last resorts** - criticizing the draft law on mandatory mental health care, comparison with current law BOPZ and description of a concrete alternative: the Eindhoven Model (6 September 2010)
- **The Eindhoven Model for supported decision making - by using Family Group Conferencing in and to prevent crisis situations in the field of mental health** (revised version in cooperation with *Eigen Kracht-centrale*: 2010)

interaction with the social environment. Psychosocial problems are mainly social problems, closely related to one's social background and circumstances, featuring tension between the person and society.

It is evident that the social environment has a crucial positive or negative impact on mental health. Social factors contribute largely to recovery from psychosocial problems. Recovery does not mean cure. The recovery approach⁷, which is flourishing since the 1990s, focuses on the personal journey to achieving a satisfying, hopeful, and meaningful life even with limitations or barriers. Mental health is not static, and coping with psychosocial barriers is highly related to the social context, including social opportunities for personal existence, development and inclusion and the intrinsic experience of wellbeing. Understanding that people who face psychosocial disabilities are people who are interacting with their environment, and that life is dynamic, is the cornerstone of understanding the concept of recovery and mental health. Recovery from psychosocial disabilities is not an isolated process for the person concerned, but rather an issue of opportunities in life, closely related to acceptance and inclusion.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is the latest binding international standard for the rights of persons with disabilities. The CRPD puts forward a view that disability is seen as the result of the interaction between a person and the barriers posed in his/her environment⁸, and that disability is not something that resides in the individual as the result of some impairment.⁹

Mental health and psychosocial disabilities cannot be separated from the person's social context. The community is a vital part of any psychosocial barrier. Psychosocial disabilities can be seen as a synonym of social exclusion, while on the other hand, recovery is characterized by countering exclusion and enabling inclusion.

Care is social support: from exclusion to inclusion

Ideally, the overall aim of mental health care, with a recovery-oriented view and a human rights based approach, is to support an optimal symbiosis in life in the community where persons can reach full potential while participating in an inclusive environment which respects diversity and offers meaningful opportunities to achieve a happy and fulfilling life. The core goal of mental health care is to support psychosocial recovery-processes.

Contrary to medical diagnosis, psychosocial problems have no single source which can be treated as the origin of all the symptoms (like an infection). Behaviour and feelings have multiple reasons, functions, causes and intentions. Psychiatry is therefore not a medical science, but (psycho) social work. However, the movement of social psychiatry is not yet prominent in psychiatric care developments. Since the past decades, the biomedical approach has dominated and severely narrowed the view of mental health by putting the primary focus on the brain as the part where psychological attributes (of the mind) are located, which is meaningless because the proper subject matter can only be the whole human being (in the context of life). Biomedical models create the option to neglect interaction, by simply medicalizing behaviour and disconnecting it from the social dimension, which devalues human experiences. This is further enhanced by the fact that social attitudes, local dynamics and contact are not suitable for statistic research and a commercialised approach, which in current times creates a complementary tendency to omit the social dimension in mental health care.

⁷ Recovery is a journey of the heart, Deegan 1996 <http://www.bu.edu/cpr/repository/articles/pdf/deegan1996.pdf>
Conspiracy of Hope, Deegan 1987 https://www.patdeegan.com/sites/default/files/files/conspiracy_of_hope.pdf
Recovery... the guiding vision in the 1990s <http://128.197.26.36/cpr/repository/articles/pdf/anthony1993.pdf>
Wellness Recovery Action Plan (WRAP) : <http://www.mentalhealthrecovery.com/wrap/>
research on WRAP <http://www.mentalhealthrecovery.com/wrap/research.php>

⁸ Evolving concept of disability: CRPD preamble (e), Article 1

⁹ CRPD Handbook for Parliamentarians <http://www.ipu.org/PDF/publications/disabilities-e.pdf>

The neglect of social dynamics and the dominant practice of medicalization of behaviour gives false justifications of forced interventions under the pretext of care and so-called best interest, while forced interventions are harmful and traumatizing, due to deprivation of interaction, power imbalances, social exclusion, detachment and dehumanization. Forced treatments therefore oppose real mental health care. It is important to acknowledge social dynamics and interconnectedness, to enable an open mind for finding real effective and supportive solutions for dealing with psychosocial crisis situations.

Coping capacity in crisis situations

Psychosocial crisis situations are generally accompanied by psychological suffering and social isolation of the person involved (often referred to as “*sliding down*”), and on the other hand, a society which demands intervention, because social support is exhausted or absent. In other words, crisis situations occur when the impact of a certain behaviour is not meeting the coping capacity of the social surroundings (or vice versa). Disability comprises both ends of the interaction, and a crisis occurs when the social tension exceeds the coping capacity. Psychosocial problems, tensions and disabilities do not reside solely in a person, but are strongly related to the coping capacity of the community.

Psychosocial problems are related to various mechanisms of social exclusion. Odd behaviour often induces feelings of fear, vulnerability, social rejection, a desire to keep control, to intervene and maintain the social order. Polarization between various stakeholders might eventually result in a call for exclusion, such as by (forced) intervention. In many cultures this polarization can lead to disownment of capacity, which is often rooted in a desire to keep social control, and a misinterpretation of ‘safety’.

However, forced interventions do not solve social tension, and neither do they bring safety – in fact, they result in the opposite: increasing social tension and less peace and safety.

Coercion is not supportive

Coercive interventions have no therapeutic basis and are not designed to improve the wellbeing of the user. Coercion in psychiatry originates in powerlessness for both the user and the carer, who are at a loss of ways to deal with the situation otherwise. In fact it is panic answered by panic, which leads to more mutual panic, disappointment, despair and so on. Many users and carers are traumatized by this continuous struggle, and if it were possible, everyone would prefer to avoid coercive interventions. So what is needed is to increase knowledge and skills to handle psychosocial crisis situations in another way.

There is no “one-size-fits-all” solution. Mental health is personal. So-called ‘*dangerousness caused by mental illness*’ does not exist. The actual crisis situation is caused by social tension often induced by overwhelming feelings of powerlessness, fear, anger, panic, despair, grief etc. and a lack of support and social chances. Any behaviour has a reason or cause, and results from personal and social experiences, character, surroundings and so on. Also problematic behaviour always has a reason of any kind, social or intrinsic, such as pain, abuse, fear, powerlessness, lack of opportunities, lack of social understanding and social support and so on. The first step is always to find out what is going on, what is the cause of the negative experience, and to try to relieve the tension.

Repressing people does not put an end to psychosocial problems. On the contrary, psychosocial problems increase. This does not increase safety; it causes more struggle. A real experience of safety relates to the absence of a struggle, also called peace. The focus of care in psychosocial crisis situations should be on restoring peace. Care is compassion. Non-violent de-escalation skills are needed.

Alternative approach

Instead of just prohibiting certain behaviour, and repressing, restricting and punishing persons for it, there is a need to de-escalate the cumulated social tension by paying attention to inner motivations and social dynamics. Contact and communication are key to find out what is going on in a certain situation.

A list of collected guidelines to stimulate de-escalation in a crisis situation¹⁰ :

- Take care of the cause, not just the symptoms.
- Do not postpone wellbeing and recovery processes.
- Find out what's going on: Psychosocial problems are highly related to social circumstances: Enable social contact and communication
- Provide support to solve psychological and social tensions
- Do not resort to forced interventions.
- There is no mental health crisis when there is wellbeing.
- Take time and attention
- Create safety by stimulating peace.
- Think outside the box, be flexible and enable support on an individual level.
- Focus on opportunities
- Never let go of hope: Every person can experience wellbeing, and a crisis will pass. Social inclusion and peace are possible.
- If you cannot relate to the person involved, find someone who can
- Don't stop looking for solutions

Wellbeing is not that complicated (but medical mental health care often makes it complicated) The power of a good conversation, of feeling understood, feeling loved, feeling you are not alone, the hope that bad times will pass, the feeling of growth, challenges, recovery and the glory of overcoming trouble, having new chances, and social meaningfulness all can have a tremendous positive impact on someone's life.

Communication is far more evidence-based than coercion. User experiences and projects^{11, 12} to reduce coercion in mental health care show that successes in reducing coercion are achieved by social approaches. These projects put an emphasis on social relations, nearness, involvement, contact and trust and true negotiation, where the will and wishes of the user are central. This demands bigger efforts, more time and more attention than the previously regular way of fighting a crisis. Aspects such as attitude, communication and a social approach with attention for social circumstances and dynamics have proven to be keys in changing the repressive practices.

In crisis situations, efforts should be made to re-establish contact, hope, chances and peace, to stop the panic from growing. A focus on wellbeing and a recovery-supportive approach are crucial aspects of good care practices.

Need for "Prima Remedia" instead of "Ultimum Remedium"

Crisis situations generally develop over time, and because of this gradual development, prevention of crisis situations is possible. Forced interventions are said to be a last resort (the so-called *Ultimum Remedium*). However, there seem to be no first resorts (which we call *Prima Remedia*).

¹⁰ Based on experiences and national and local projects to reduce coercion: *Projecten dwang en drang*

¹¹ *Project dwang en drang* : publicatie LPGGZ (user and family umbrella organization): Opsluiten is geen zorg (2008) <http://www.platformggz.nl/lpggz/download/lpggz-reacties-persberichten-rapporten-etc/publicatie---opsluiten-is-geen-zorg.pdf>

¹² *Project dwang en drang* : VUMC/GGZ Nederland: Best practices rondom dwangreductie in de geestelijke gezondheidszorg (2011) http://www.veiligezorgiederszorg.nl/speerpunt-dwang-en-drang/ggz_n_d_d_5.pdf

In many complex psychosocial situations, there is an overall lack of prevention, lack of personal attention and a lack of skills and expertise in mental health care. Skills for non-violent de-escalation are not well-developed, due to the entrenched practice of restraint, seclusion, and forced medication of persons in mental health care. The practice of coercion has caused destruction to the learning process of how to deal with persons in crisis situations. Communication and contact skills have not been developed within the context of forced treatments.

In crisis situations, there is often no way to get urgent access to voluntary, desirable support services in the mental health care domain: Only the “last resort” (forced intervention based on the *Mental Illness-principles*¹³) is available on an urgent basis. This leads to a situation where a person can be suffering from psychosocial problems, and the society is waiting for it to get worse, until the situation reaches a certain degree of severity. Then a horrible intervention is initiated, which does not help the person or the population. This way of handling psychosocial crisis situations is morally wrong, as it does not lead to wellbeing, health or safety, and it causes neglect in various ways.

There is no prevention and no adequate anticipation on psychosocial crisis situations. The repressive approach of psychosocial crisis situations constitute lamentable remnants from the past. This is not care. This is neglect! What is needed is personal voluntary, desirable support in the earliest possible stage, and non-violent de-escalation of crisis situations. We need real solutions: “*Prima Remedia*” instead of the *Ultimum Remedium*.

Answering a psychosocial crisis with forced intervention is wrong. Besides the fact that coercion does not increase the wellbeing of the population, coercion is also a violation of international human rights laws and conventions, such as the UN CRPD.

Human rights approach

The UN Convention on the Rights of Persons with Disabilities (CRPD) is a long-awaited breakthrough that recognizes persons with disabilities, including persons with psychosocial disabilities, in all their diversity, as equal human beings with the same fundamental human rights as others. This includes the right to exercise legal capacity, to liberty, to physical and mental integrity, to be free of torture and ill treatment, and to health care on the basis of the individual’s free and informed consent. These fundamental rights imply a ban on all forced treatments, which was also explicitly stressed by the UN Special Rapporteur on Torture and Other Cruel Inhuman or Degrading Treatment or Punishment¹⁴. The CRPD provides a momentum for revolutionary change in attitudes and practices towards persons with disabilities. While the Netherlands has not yet ratified the CRPD, it has signed it which is a signal of the political intention to abide by it. The CRPD has been ratified globally by 134 countries, 25 out of the 28 members of the European Union, and ratified by the European Union itself, representing the first international human rights treaty to which an intergovernmental organization is a party. I embrace the CRPD and decided that my own alternative model would have to comply with these latest international standards.

Core value: persons themselves are the experts of their own lives

Each person is unique. The richness of diversity is contained within each individual. The importance of valuing and respecting individual differences in all the citizens of the world, and recognizing the unity of humankind cannot be stressed enough. The principle of respect for diversity is rooted in the recognition that all persons have their own identity. People are entitled to having their own perceptions, feelings, experiences, realities, character and so on. The firm belief that persons themselves are the experts about their own lives is reflected in the call to respect diversity. This core value is further reflected in the right to legal capacity, which also acknowledges that persons themselves are the experts about their own lives, by giving people the legal right to decide for themselves according to their own will, choices and preferences. Having independent authority over your own affairs and decisions is a core human right and principle.

¹³ WHO document *Principles for the protection of persons with mental illness* (1991), superseded by the CRPD in 2008

¹⁴ Mendez 2013, A/HRC/53/22

(Pre)Design of the Eindhoven Model

After generating my vision and discerning key values, I identified several principles which had to be met to deal with crisis situations in a consensual way. These principles formed a list of key demands and criteria that I put to myself, which are shown in the table below:

Table 1. List of key demands and criteria:

Main Question: How to shape an alternative decision-making model? Sub-questions:	Goals and sub goals: A decision-making procedure:
<ul style="list-style-type: none"> ○ How to do right to users and communities? ○ How to generate a situation with maximum satisfaction and agreement and minimal complaints? ○ What reflects the wishes and needs of a person and his or her environment? ○ How to come to a good definition of the problem when there is a variable (not standardized) need for support? ○ What is the best way to get an overview of a person's complex situation? ○ How to find alternatives? Where are the opportunities? ○ How to build on personal gestures, the character and the natural coping mechanisms of a person? ○ How to get information and insight about the personal characteristics of the person concerned? Who can help with that? ○ How to communicate with the entire chain of involved stakeholders? ○ What is worse: talking about taboos or deprivation of freedom, and coercion? ○ How to offer more safety to users, and stimulate participation and information-sharing in the process? ○ How can the persuasiveness of close persons with good intentions be used in mediation? ○ What are the options for supporting the user better in this process? ○ Which quality criteria can be applied to the decision and the sub topics? 	<ol style="list-style-type: none"> 1. with maximum attention to alternative solutions (<i>Prima Remedia</i>) 2. with maximum satisfaction and agreement and minimal complaints from all involved stakeholders 3. where the rights for users and their communities are optimized. 4. With maximum respect for the wishes and needs of a person and his or her environment 5. with a good definition of the problem when there is a variable (not standardized) need for support 6. with the best possible overview of the situation of the person 7. where alternatives and opportunities can be found 8. with opportunities to build on personal gestures, the character and the natural coping mechanisms of a person 9. with opportunities to get information and insight into the personal characteristics of the person concerned 10. with maximum communication among the entire chain of involved stakeholders 11. with more safety for users, and maximum participation and information-sharing during the process 12. with chances to apply the persuasiveness of close persons with good intentions in mediation 13. with maximum possibilities to support the user better in this process 14. where quality criteria are/can be applied to the decision and the sub topics 15. in line with the principles of the UN CRPD 16. which enables connection and optimization regarding the context of the draft law on 'Mandatory Mental Health Care'

For dealing with psychosocial problems a social community-based approach, aimed at inclusion and wellbeing for the individual and the social surroundings is needed.

Finding an alternative approach

I had arrived at the stage of exploring and imagining possible solutions. At a certain point, I remembered a piece of information about *Family Group Conferencing*. I looked it up and analysed it further. According to my view, Family Group Conferencing would fit the needs of an inclusive and empowering approach of persons who want to find their way out of a psychosocial crisis situation. After studying and reflecting on the principles and practices of Family Group Conferencing, I wrote a report (2009) which described an alternative proposal to deal with psychosocial crisis situations by using Family Group Conferencing. I called it: *The Eindhoven Model*. Shortly after publication, I was contacted by the Dutch organisation for Family Group Conferencing (*Eigen Kracht-centrale*¹⁵), who were interested in starting a pilot project on the Eindhoven Model.

¹⁵ www.eigen-kracht.nl

What is Family Group Conferencing?

The Eindhoven Model is based on using Family Group Conferencing in psychosocial crisis situations. Instead of executing undesirable interventions, such as forced psychiatric treatments, the aim is to identify a range of desirable solutions on an individual level by Family Group Conferencing. Note that “Family Group” is not limited to family, but refers to friends, neighbours, peers and any important person in one’s life, as in “extended family”. Family Group Conferencing is a voluntary consultation process around a key question.

The origin of Family Group Conferencing in the 1980s in New Zealand

The indigenous Maori population experienced having their land forcibly taken away, and then their children who were forcibly placed in institutions by the New Zealand government. This caused huge resistance among the Maori population towards the government. The New Zealand government came to the insight they could not ignore this deep-rooted resistance, and together with the Maori population they invented Family Group Conferencing.

The fact is that the government sets certain laws, such as on safety for children. The existence of a legal framework or condition is built in into Family Group Conferencing. This means there can be a rule, such as “no violence” or “ensure safety”. However, the key question “How to do this?” was forwarded to the Maori population, who gathered a circle of wise and involved citizens to think about a plan, while bearing the framework in mind.

The circle of people talked about this question, in their own language and while applying their own values. They made a plan, and the New Zealand government accepted this plan, because it met the conditions set for basic safety. In this way, the Maori population could retain ownership over their lives, and were allowed keep their own children safe. They knew what was expected from them, and they were able to find their own way to deal with these government’s laws.

By now, Family Group Conferencing is a widely recognized way of decision making, and a way of respecting citizens. There is an independent organization for Family Group Conferencing¹⁶, which purely aims to facilitate Family Group Conferences, and includes research¹⁷, communication and training. The independent Family Group Conference -network comprises several active Family Group Conference -organizations in quite some countries in the world, although the implementation scale varies a lot.

Self-determination within a wider social structure is one of the core principles embedded in Family Group Conferencing.

Family Group Conferencing comprises 4 main steps or stages:

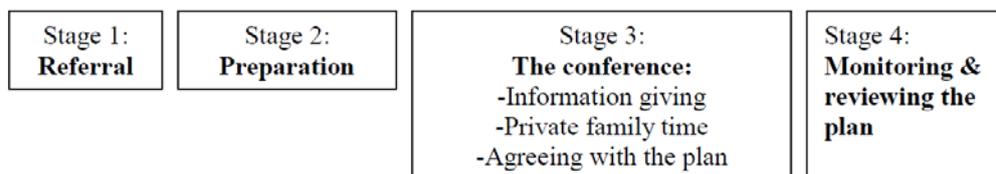


Illustration 1. Family group conference model (Source: Hayes & Houston 2007, p. 995).

Discussing a key question together

Family Group Conferencing is a voluntary consultation process around a key question. The main principle of Family Group Conferencing is to widen the circle of people, and engage everyone who is involved, because everyone can contribute. The family group refers to the circle of one’s “own people”: persons who are part of the life of the main person, such as friends, family, neighbours, and important others. Because they know each other, there is a deeper level of contact and understanding, which can support the main person directly, but also helps in identifying other support potential.

¹⁶ Family Group Conferencing network in Europe <http://www.familygroupconference2011.eu/en/home/>

¹⁷ List of research NL/EN: http://www.eigen-kracht.nl/sites/default/files/20120726_Overzicht_onderzoeken_naar_EK-c.pdf

Making a plan

By Family Group Conferencing, people make a plan together with their own circle. They share information to come to a good mutual understanding of the identified key question and the goal of the conference. In the *Private family time*, they identify together what is needed according to their own insights, and which steps should be taken to achieve this. The actions are listed and a plan is composed, which addresses a self-determined answer to the key question. The main person has a final say, because it is about his/her own life.

Voluntary consultation

Family Group Conferencing can only be done on a voluntary basis, as it is basically a tool for people to increase control over their own lives. It is an offer, not a plight to consult with others. It is an option which can be used by persons who want to take ownership of a problem, or rather a challenge, because the focus is not on analysing negative processes, but on achieving a better life by fulfilling a certain wish, which is put as the key question.

With and without a framework

Family Group Conferencing can be initiated with or without a legal framework or condition. Family Group Conferencing unfolds around a main question in life, such as: *How to overcome a certain challenge? What is needed to fulfil a certain wish?* An example of a key question might be: *What needs to be done to enable me to live in the community independently?* This question can be discussed by the main person and his/her own circle of persons who are involved. They are, of course, the real experts on the particular individual situation. Together they can find ideas and compose a plan which sets out which steps need to be taken, in order to answer the key question. So for example: *Who will do what and when in order to enable independent community living?* Often persons themselves know very well what they really need, and the creativity of a family group should not be underestimated. Generally, the more people, the more ideas.

Family Group Conferencing can also be done with a framework or legal condition, but also only when the main person(s) agree on this goal. By Family Group Conferencing, the person consults with his/her social network to find answers to a key question, such as: *What is needed to avoid or handle certain problematic situations?* When there is a legal restriction or condition of a certain kind, this can be incorporated as a framework that needs to be taken into account in the Family Group Conference. Experience shows that generally the agreed frameworks are about safety, imposing limits such as no more domestic violence or no more abuse. Sometimes the main question concerns how to avoid a social disturbance. A framework implies certain conditions or minimum requirements which need to be met by the plan in order to make it a safe and acceptable plan. When for example, the key question is about ending domestic violence within a mandatory framework, a minimum requirement would be that the plan would need to address: *What will be done to ensure safe living, including which actions will be taken when there is any safety-risk.*

No force - only care

Family Group Conferencing can only be done successfully when the participants are truly committed and willing to achieve the goals of the conference, which makes them dedicated to make their own plan and to execute identified steps to improve their own lives. Participants need to be willing to search for balance in living in their communities together, and be willing to listen and respect each other's will, values, preferences, and choices, and to make efforts to come to a mutually agreed plan with their own circle of people.

Family Group Conferencing cannot be used to discuss "which forced psychiatric interventions a person will be subjected to". Forced treatment is not an option: it is illegal under international human rights law¹⁸. The focus should be on finding desirable solutions which support the person concerned and his/her social surroundings. Family Group Conferencing can be a way to identify

¹⁸ See: Convention on the Rights of Persons with Disabilities and the report A/HRC/53/22 Mendez (2013)

desirable solutions in situations of psychosocial problems, even in crisis situations, because these are very closely related to social dynamics in the person's life. In general, the persons close to the main person are the best listeners, especially in harder times.

The illustration shows two scenarios of Family Group Conferencing: with and without a framework:

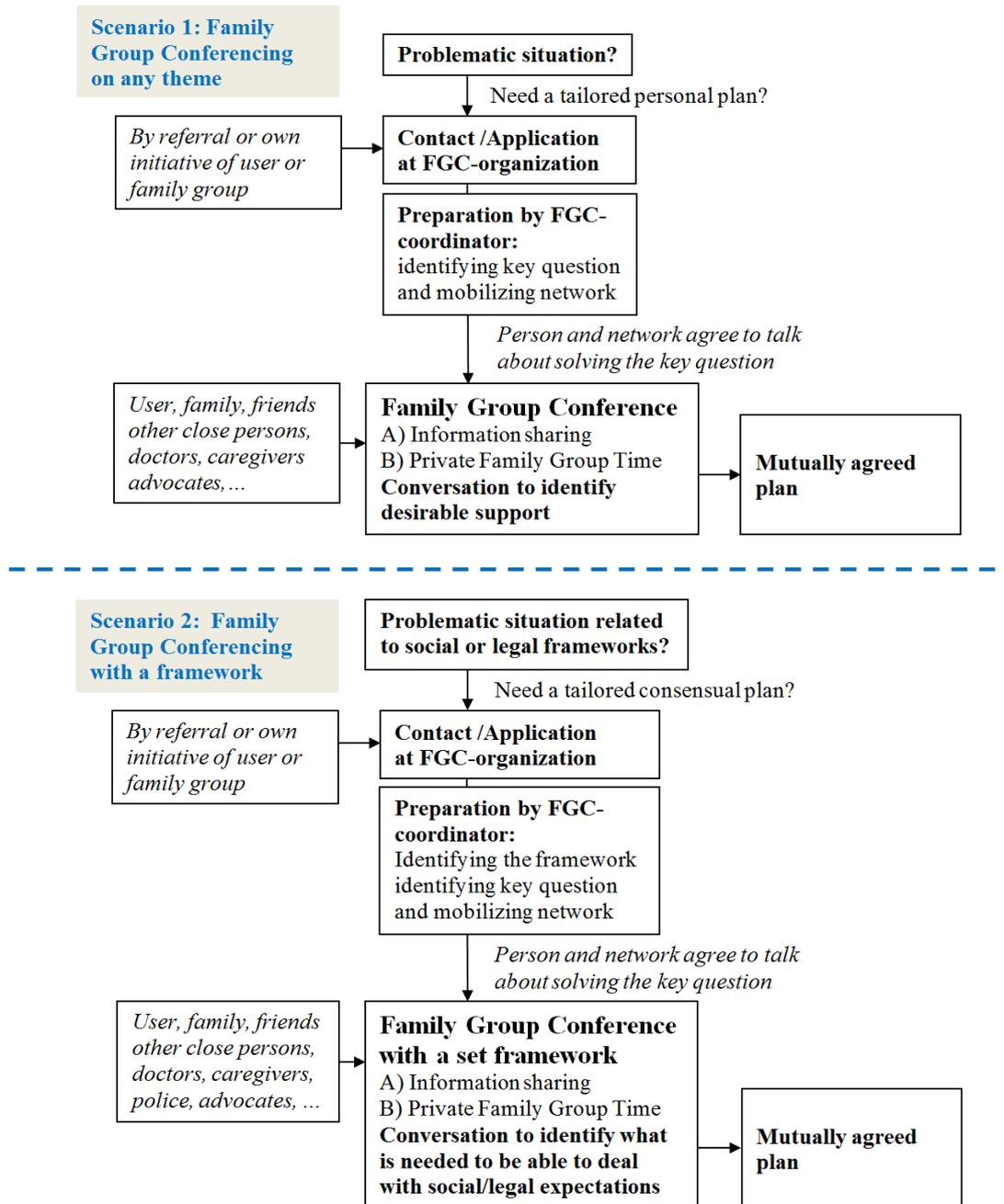


Illustration 2: Family Group Conferencing (FGC): Scenario 1: FGC without a framework, Scenario 2: FGC with a framework

Various stages of Family Group Conferencing:

Application

Family Group Conferencing can be considered when someone faces a problem or challenge in life. In the Netherlands in 2012, around 83% of Family Group Conferences started after referral by professional caregivers (This is partly because many laypersons are unaware of the possibility of Family Group Conferencing). The remaining 17% of conferences were initiated on the own application of citizens. In 25% of all applications psychosocial problems played a role and in 15% of applications an intellectual disability played part.¹⁹

¹⁹ Dutch annual report: Eigen Kracht-centrale in Vogelvlucht 2012 : <http://www.eigen-kracht.nl/nl/inhoud/jaarverslagen>

Preparation

Upon application, a coordinator from the Family Group Conferencing-organization will be selected to take care of the organizational processes. The coordinator is independent and has no relation to the outcome of the plan. The job of the coordinator is to make the Family Group Conference a success by enabling the group of persons to make their own plan. The independence of the coordinator is very important and therefore there is an independent organization for Family Group Conferencing, which purely aims to facilitate Family Group Conferences.

The coordinator will analyse the situation and helps phrasing a key question to which all participants can agree. When there is a framework or condition which needs to be taken into account, the coordinator will analyse the conditions and makes sure that this mission is reflected in the main question.

The coordinator also helps to identify who could be invited, and if necessary, helps with the invitations. The main person has a final say, because it is about his/her own life. When participants agree to join the conference, the coordinator will take the lead in planning the physical conference.

The conference

The conference takes place on a neutral ground which comforts the individual and cultural needs of the group. Often this is a private room in a public facility, such as in a bar or a church nearby. The presence of self-selected food and drinks strengthens the informal atmosphere of the conference, and contributes to a family experience. In this way, all participants can feel safe to talk openly, and nobody is distracted by other duties and is enabled to focus on the topic and connect to each other.

Information sharing

The conference starts with the sharing of information which can also include views from professional caregivers, such as their analysis and which support they can offer. Sharing information includes sharing all relevant perspectives on the main question which is central at the conference. It is very important to have a good understanding of the situation, the dynamics and the challenges, before jumping to conclusions. Especially in mental health care, the sharing of information and analysis of the social situation is often neglected by presumptions based on diagnosis which leads to narrow-minded views and an inadequate social analysis. However, there is meaning behind every behaviour. Psychosocial problems vary over one's lifetime and no situation is the same. An open mind is needed to understand what is going on at that particular time in life. Often the close persons are the best listeners, which makes Family Group Conferencing a promising tool for the mental health care sector. By sharing information in the first stage of the conference, all participants get all the information they need to understand the key question, and everyone knows what is expected from them. After sharing information and exchanging views, all participants understand the topic that needs to be discussed in the private family time.

Private family time

At the private family time, all the outsiders leave, and then only the person and his or her own circle of people remain. They can talk freely in their own language and discuss options. Because people already know each other, it is easier to open up in conversations within their own circle; people can be themselves as they are in their daily lives. Often friends and family are able to relate to the user by understanding their character, their life experiences and ways of coping in other situations, which offers a great potential for creating understanding and finding real appropriate support. Also expressing love and willingness to support is surely healing. Communication is the key for living together in peace, and therefore communication is equally the key in dealing with mental health crisis situations and preventing exclusion.

In the private family time, a plan is made by the family group themselves.

The own plan

Support by both formal and informal care can be combined in the plan. The substance depends fully on the wishes and the requests of the person(s) concerned. In 68% of all plans there is a demand for professional care, in 32% of plans there is no such demand.

The coordinator will check whether the plan meets the criteria for a practically useful plan, which mostly means checking whether appointments are giving a full answer to the main question, and whether appointments are concrete enough to be executed and checked.

The plans made by persons themselves, while supported by their circles of family, friends, neighbours and other important people, are often very practical, cross-sectional, clear, simple and to the point. Especially in situations with multiple needs, generally the professional carers tend to get lost (because of a sectional approach), but the persons involved can often think of very practical and effective community-based solutions, which grab at the roots of the series of problems and consequences. They know what would help them (for example: getting a job, a meaningful social life, no more financial stress and so on).

The plan describes which actions need to be taken, when and by whom. All participants get a copy of the plan, which they all sign for agreement. The plan is owned by the family group themselves. In 86% of cases the execution of the plan is performed and monitored in the own circle, and not by professionals. The coordinator only has a copy for administrative purposes, but is no longer involved, except to carry out an evaluation contact after several months.

Monitoring and reviewing the plan

After a set period of several months, the coordinator will contact the family group again to check whether the plan and the entire process of Family Group Conferencing has had a satisfying outcome.

Some research data from the Dutch organization on Family Group Conferencing^{20, 21, 22}

- On average 3,7 problems play a role when Family Group Conferencing is initiated.
- 2/3 of participants are of the opinion that the situation improved. About 15% are of the opinion that it remained the same. 5% found deterioration and 10% had no specific opinion or had no view on the current situation. No difference between main persons, applicants or family members is noted. On average: Participants value Family Group Conferencing with 7,5 out of 10 points.
- Reduction of care-consumption: In New Zealand, where Family Group Conferencing is a legal right, the use of Family Group Conferencing has led to great changes: The number of children under governmental care reduced by 60%, the number of network-placements has increased and the number of legal measures has reduced drastically.
- Family Group Conferences promote social cohesion. A Family Group Conference generally has 10-15 participants. The increase in social cohesion stabilizes after the conference and is still notable after 9 months.
- On average, 80% of the appointments in the plans are on account of the family and acquaintances. They form an important source of support. Follow-up research shows that the majority of the offered support is actually given. The majority of the plans are executed or partially executed (71%). Family Group Conferencing and executed plans lead to various processes and outcomes, such as the sharing of experiences, emotions, information and worries in the social network, an improvement of the situation, the feeling of the main person of not standing alone in it and an improvement in the handling of problems by the main person supported by the social network.
- Research conducted on 100 Family Group Conferences in Amsterdam showed that 96% of Family Group Conferences lead to actions by family and network, which otherwise would not have been done by professionals.

²⁰ [http://www.eigen-kracht.nl/sites/default/files/20111200_Jeugdbeleid_Opbrengsten_en_effecten_EK-conferenties_\(M.Schuurman\).pdf](http://www.eigen-kracht.nl/sites/default/files/20111200_Jeugdbeleid_Opbrengsten_en_effecten_EK-conferenties_(M.Schuurman).pdf)

²¹ http://www.eigen-kracht.nl/sites/default/files/20130306_Opbrengst_EK-conferenties_resultaten_en_baten_0.pdf

²² Dutch annual report: Eigen Kracht-centrale in Vogelvlucht 2012 : <http://www.eigen-kracht.nl/nl/inhoud/jaarverslagen>

Family Group Conferencing: the potential to avoid forced treatments?

As previously explored in my vision: The social context cannot be left out when dealing with mental health or psychosocial problems, or disabilities, or life in general. Coercion and exclusion do not lead to wellbeing. Instead of top-down coercive legislation, a social community-based approach, aimed at inclusion and wellbeing for the main person and the social surroundings is needed.

By comparing the requirements (key demands) with the features of Family Group Conferencing, it seems likely that Family Group Conferencing meets the demands and has the potential to enable alternatives to forced treatments.

Table 2. Comparison of key demands and the features of the Eindhoven Model/ Family Group Conferencing

Key demands: Identified goals and sub goals for an alternative model	Features of the Eindhoven Model / Family Group Conferencing
o A decision making procedure	• FGC: a way of making decisions / making a plan
1. with maximum attention to alternative solutions (<i>Prima Remedia</i>)	• FGC: not focussed on forced interventions, but on desirable care (<i>Prima Remedia</i>)
2. with maximum satisfaction and agreement and minimal complaints from all involved stakeholders	• FGC: process and plan is mutually agreed by all involved stakeholders
3. where the rights for users and their communities are optimized.	• FGC: promotes self-determination, is based on voluntariness, and focuses on desirable support of both the main person and the social context
4. With maximum respect for the wishes and needs of a person and his or her environment	• FGC: focuses on the self-defined wishes and needs of a person and his/her network
5. with a good definition of the problem when there is a variable (not standardized) need for support	• FGC: the persons themselves are the experts: self-determination of questions and support
6. with the best possible overview of the situation of the person	• FGC: the persons themselves are the experts : the person and network have the most detailed overview of the situation of the person
7. where alternatives and opportunities can be found	• alternatives and opportunities can be found by a social approach: communication and social support – FGC enables social consultation
8. with opportunities to build on personal gestures, the character and the natural coping mechanisms of a person	• FGC: the persons themselves are the experts: main person and network know about personal gestures, the character and the natural coping mechanisms of a person
9. with opportunities to get information and insight into the personal characteristics of the person concerned	• FGC: the persons themselves are the experts: main person and network have information and insight into the personal characteristics of the person concerned
10. with maximum communication among the entire chain of involved stakeholders	• FGC: meeting with the entire chain of involved stakeholders
11. with more safety for users, and maximum participation and information-sharing during the process	• FGC: user stays in control (safety for users), voluntariness stimulates participation and information sharing during the process
12. with chances to apply the persuasiveness of close persons with good intentions in mediation	• FGC: meeting with the social network offers chances to apply the persuasiveness of close persons with good intentions for mediation
13. with maximum possibilities to support the user better in this process	• FGC focuses on supporting the main person
14. where quality criteria are/can be applied to the decision and the sub topics	• FGC is facilitated by a credible accredited NGO, using a standardized framework and quality monitoring by evaluations, research and training
15. in line with the principles of the UN CRPD	• FGC: respects the principles of the UN CRPD : promotes legal capacity and diversity, and enables supported decision making.
16. which enables connection and optimization regarding the context of the draft law on 'Mandatory Mental Health Care'	• the Eindhoven Model / FGC can replace the draft law on 'Mandatory Mental Health Care', and replace substitute decision making by supported decision making

Reflection on the specific features of Family Group Conferencing

- Family Group Conferencing originated by a desire to protect people from unwanted government intervention, which is certainly relevant for mental health care.
- Family Group Conferencing can be used in mental health care, also in psychosocial crisis situations:
 - The social tension and social polarization in psychosocial crisis situations can be addressed as a key question for Family Group Conferencing.
 - By Family Group Conferencing, a tailored plan for desirable support (*Prima Remedia*) can be identified, ending the structural emotional neglect.
 - Family Group Conferencing can be applied in situations with and without perceived 'dangerousness', which enables prevention of crisis, ending the neglect of early stage psychosocial crisis situations, and making forced psychiatric interventions belong to the past.
- Family Group Conferencing is an empowering way of decision making; It focuses on desirable support for a person or family group, and the outcome is a consensual plan.
- Experiences tell us that during forced interventions, the entire social network suffers. Therefore, we assume that it is possible to get everyone willing to think about alternatives and desirable support all together.
- A procedure based on Family Group Conferencing can replace the law on forced treatments, by enabling supported decision making, instead of substitute decision making, in accordance with article 12 of the CRPD (legal capacity).
- Family Group Conferencing can be a way to facilitate the right to legal capacity and supported decision making, and other human rights, such as living independently in the community (CRPD article 19) and reasonable accommodation.

Moreover, Family Group Conferencing is a way of thinking. In its core, Family Group Conferencing is embracing the stance that persons themselves are the experts over their own lives, and values the interconnectedness of people in life. This corresponds with the very basic principles of the human rights based approach (diversity, legal capacity), and also with the rights, views and spirit embedded in the CRPD (legal capacity, supported decision-making).

Family Group Conferencing embodies the principle that persons themselves are experts over their own lives. This way of thinking implies a culture shift in organizing care systems: instead of seeing persons as "objects" of treatment, it ensures empowerment and capacity to the individual as the "subject" and seeks for self-defined solutions and to facilitate these. This means professionals need to step down, and take the self-made plans as a guidance for all professional care. It needs to be acknowledged that the person with his/her circle has the real expertise, not the professional. This is not just an peripheral side-note. This is a real challenge.

The approach of Family Group Conferencing has the potential to enable a culture shift in mental health care systems and in communities, and can provide an alternative to the incapacity-approach and the practice of forced treatments, by facilitating supported decision making.

Above all, Family Group Conferencing can be a way to identify and organize desirable solutions, which brings us all closer to a world with full human rights for all.

I found myself more and more convinced of the powers of Family Group Conferencing. In October 2010, in cooperation with *Eigen Kracht-centrale* (Dutch FGC-organization), my vision-document of 2009 was updated into a revised version (2010): The Eindhoven Model for supported decision making by using Family Group Conferencing in and to prevent crisis situations in the field of mental health.

Pilot project

In the Netherlands, together with the Dutch organization of Family Group Conferencing (*Eigen Kracht-centrale*), we started a pilot project on the Eindhoven Model.

In 2010, we started setting up a local pilot project in the city Eindhoven (my residence).

Since March 2013, this pilot project has expanded and is now co-funded by the Ministry of Health.

This pilot project is referred to as: **The Eindhoven Model for supported decision making - by using Family Group Conferencing in-/ and to prevent crisis situations in the field of mental health.**

In this pilot project, we offer Family Group Conferencing in psychosocial crisis-situations – instead of forced interventions. In practice, this means that instead of mobilizing two independent psychiatrists for a psychiatric screening and a procedure for legal assessment whether non-consensual interventions would be allowed (based on the outdated *Mental Illness-Principles*²³), as the alternative, by Family Group Conferencing, the person's network is mobilized to help finding desirable social solutions, corresponding to the person's will, autonomy and preferences. Through the Family Group Conference, these persons can consult with their own people, of their own choice, in order to make their own plan on what can be done and what is needed to overcome a crisis or to avoid escalation.

Since 2013, this pilot project includes three regions in the Netherlands: Eindhoven, Groningen and Noord-Holland-Noord, with support from the mental health institutions at these locations (*GGzE, Lentis* and *GGZ Noord-Holland-Noord*), and supported by the national branch-organization *GGZ Nederland*. The pilot project also includes academic research on the effects of applying Family Group Conferences in psychosocial crisis-situations (done by the Free University Medical Centre *VUMC* in Amsterdam). The pilot project is positioned under community mental health, to avoid forced institutionalization and to avoid the start of forced treatments. The very few first results of this pilot project are promising.

Family Group Conferencing in practice

The following description of a psychosocial crisis situation where Family Group Conferencing was applied successfully, is derived from the article: *Breaking through Marginalisation in Public Mental Health Care with Family Group Conferencing: Shame as Risk and Protective Factor* – by Gideon de Jong and Gert Schout²⁴:

Case 1: social isolation and alcohol addiction

The first case is about a sixty-six-year-old man who, after his retirement, got addicted to alcohol and found himself in isolated circumstances. The addiction had led to a worrisome somatic state. A care provider referred the client to an FGC in order to mobilise support from his network. However, the client had been divorced years ago and lost contact with his ex-wife and children. Contacts with other family members were abruptly broken by conflict or had faded.

The client, aware of his deprived living condition, responded enthusiastically to the proposal of the care provider. The main aim of the conference was creating a safety net around the client in order to prevent further deterioration and offer support to get his life back on track. A co-ordinator from the local FGC organisation was appointed to organise the conference. There was a profound discussion between the client and co-ordinator about those who needed to be involved during the conference, finding a balance between supporting the agenda (mobilising enough resources to ensure the creation of a safety net) and respecting the wishes of the client. Only former colleagues were being mentioned by the client. Notable absentees on the list were his children and other family members, including his brother. After several attempts by the co-ordinator to change the client's mind, he still was not

²³ WHO document *Principles for the protection of persons with mental illness* (1991), superseded by the CRPD in 2008 as confirmed by the UN Special Rapporteur on Torture

²⁴ published at <http://bjsw.oxfordjournals.org/>

inclined to invite his family. It was decided to organise the conference with three former colleagues.

Interviews uncovered a close relationship between the client and his former colleagues. As former employees of the national postal service (in their own words, a real 'family-run business'—fathers from both client and colleagues also had a lifetime career at this company), they always took care of each other. Before the conference, the colleagues therefore did not act aloof, but they often did not know how to deal with the client's circumstances (severe contamination, poor personal hygiene, drunken and intoxicated by alcohol and therefore unresponsive). As one interviewed colleague stated:

For once, when he was on the phone and said: 'I do not know how to get out of this miserable situation', a whole day I helped him to get out of the mess. And really, there was so much rubble. I have a fairly big car, which was totally loaded with empty beer and wine bottles. That I brought to the landfill. I needed to go up and down three times, and still afterwards there were bottles left! There were about thirteen or fifteen garbage bags I could not bring to the landfill, so I left them behind. I said: 'You have to bring these bags yourself.' And for me this was an indicator, because when I asked him later on about the rubble he answered: 'No, they are still here.' And when I visited him again they were still there. And that's what I mean: it becomes somewhat difficult when he needs to act on his own initiative. He was also not physically able to do it himself, I must confess, because he was too much affected by the alcohol.

Informal support is senseless without a feasible plan. It appears that an FGC creates a platform where participants are able to confront each other with their opinions so that awareness can arise. The client reacts as follows on his colleagues' honesty:

Yes, I am confronted with their opinions. They [his colleagues] uncovered my severe conditions and made me aware of that if I would continue drinking and neglecting myself I would end up in the gutter.

The conference yielded a plan on how to break through social isolation, reduce alcohol consumption and ensure sustainable attention to his household and personal health maintenance.

One month after we collected and analysed our interview data, we organised a member check in which both client, two former colleagues, as well as the co-ordinator were present. We wondered whether enough effort was made by the co-ordinator to involve family members for the FGC. The member check revealed that the co-ordinator had sufficiently questioned the nature of contacts with family members and the pros and cons of inviting them for the conference. One of the colleagues responded as follows:

I do know some of his family. We have indicated that it would not be a wise decision to invite them for the conference as well. His family is one of the major causes of his deterioration. You can say a hundred times: 'You're responsible as well for these broken relationships', but that is a bit bluntly. Relationships with his family are so complicated that you do not want them to get involved. In general, when you give these people 1 coin they start asking for 10 coins. And B. [client] is already swindled enough by his family, so we considered it not to be a good idea. So during the conference, I and two other colleagues who never let him down during these years of deprivation were present.

As Mueser et al. (2003)²⁵ appoint, financial abuse within families where members are suffering from addiction is not unusual—a pattern also visible in this case. Co-ordinators who are organising FGCs in such situations constantly need to consider how much effort they need to invest in changing a client's mind when he or she is reluctant to invite certain members from his or her family who can play a role in the conference and provide support. Two months after the member check, we had another appointment with the client. He invited us to visit him at home. The purpose of this meeting was to discuss the major findings of this case study, as the following empirical memo indicates:

At seven o'clock at night, the client is awaiting for us outside his house. Instead of walking on two crutches, such as during the member check, he now moves around on one. He acts sharp as well. One of the former colleagues who was present during the FGC joins a short time later. Both client and colleague agree that a lot has changed for the better: abstinence from alcohol, attention to his household, going forth [alone or with friends], good contact with the neighbourhood [now that client is abstinent he does not have conflicts any more with his neighbours]. Colleagues and neighbours keep an eye on to prevent client from deterioration—like during the member check, the colleague expresses jokingly, but with serious undertone, once again:

'If I see for once again that at two o'clock in the afternoon the curtains are closed, I know what's happening inside and I'll break your legs.'

This quotation shows the sincere support from his colleague and the acceptance thereof by the client. Professionals could never use equivalent words. We continue the memo:

On the wall there is a picture of his adult daughter. Client responds emotionally when we ask about her. A conversation unfolds indicating that he is avoiding contact with his daughter because he fears rejection [for the past years he had been constantly under the influence of alcohol and therefore did not act as a good (grand)father].

In a follow-up interview one year after the conference (the FGC was organised in February 2011), contact with his daughter appeared to be restored.

Both shame and fear of rejection played a decisive role in why the client prior to the conference found himself in a downward spiral of addiction, self-neglect and isolation: shame for his living conditions, fear of being rejected by others because of his condition. On the other hand, shame also appears as an engine to become and stay abstinent and to take care of his personal hygiene and his household—there is a drive not to relapse into destructive patterns that he will feel ashamed of once again.

(derived from the article: *Breaking through Marginalisation in Public Mental Health Care with Family Group Conferencing: Shame as Risk and Protective Factor* - Gideon de Jong and Gert Schout, published at <http://bjsw.oxfordjournals.org/>)

The description of this situation shows that it is possible to use Family Group Conferencing as an alternative in a situation where forced intervention was seriously considered. It illustrates that coercive interventions can be avoided by a social approach. It also shows that even a relatively small social network can have a tremendous impact on one's wellbeing, and that broken relations can be restored.

²⁵ Mueser, K. T., Noordsy, D. L., Drake, R. E. and Fox, L. (2003) *Integrated Treatment for Dual Disorders: A Guide to Effective Practice*, New York, The Guilford Press.

Potential for other decision making moments in mental health care

In current mental health care systems, there are various decision making moments where self-determination can and should be empowered and enabled. This starts with voluntary care, but also at moments where Community Treatments Orders or forced institutionalization are considered, Family Group Conferencing can be a way to identify desirable support and solutions.

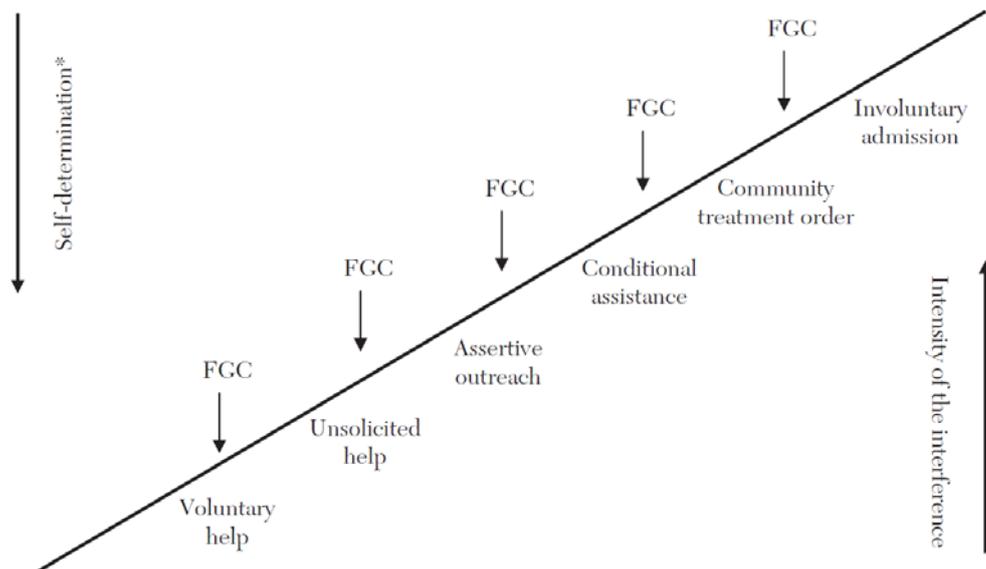


Illustration 3. Family Group Conference as a preventative tool of coercion. * when interference increases (from voluntary help to involuntary admission), self-determination decreases. FGC: Family Group Conference

Conclusions

CRPD compliant innovation of mental health care is possible

The Eindhoven Model for supported decision making by using Family Group Conferencing in and to prevent crisis situations in the field of mental health is a potential alternative to avoid forced psychiatric interventions. The Eindhoven Model takes an experience-centred approach in line with human rights principles, and embraces the core view that persons themselves are the experts about their own lives. The Eindhoven Model focuses on identifying desirable support, respecting persons and dealing with diversity in psychosocial crisis situations, and shows that CRPD compliant innovation of mental health care is possible. The Eindhoven Model can help to realize a new era of human rights, diversity and respect in mental health care practices.

Experience-based knowledge offers a new dimension to development

The Eindhoven Model is a promising example of experience-based development. The potential for the Eindhoven Model/Family Group Conferencing has been identified by reflecting on personal experiences which provides valuable knowledge for improvement and redesign of supportive services. The Eindhoven Model illustrates that using one's lived experience offers a new dimension of knowledge which can bring change to mental health care practices.

Changing mental health care practices is possible.