



THE VALUE OF TREATMENT

A family perspective on the journey through services of persons diagnosed with schizophrenia

VOT

EBC RESEARCH PROJECT
THE VALUE OF TREATMENT FOR BRAIN DISORDERS

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About EUFAMI

EUFAMI was founded in 1992 after a congress, which took place in 1990 in De Haan, Belgium, where carers from all over Europe shared their experiences of helplessness and frustration when living with severe mental ill health. They resolved to work together to help both themselves and the people they cared for.

EUFAMI is a democratic organisation, registered in Belgium as an international non-profit organisation. We have an ongoing commitment to promote the rights and wellbeing of people affected by mental ill health. We enable our member organisations to act jointly at a European Level, combining their efforts and sharing expertise.

EUFAMI is unique in bringing the distinct voice of family carers in mental health to the EU level and has a total of 35 members in 22 countries, including Russia and Israel.

About the Value of Treatment (VoT) Study

This report was developed as part of the European Brain Council (EBC) study on the [“Value of Treatment: Bridging the Early Diagnosis and Treatment Gap for Brain Disorders”](#).

The main objective of the VoT project was to assess the socio-economic impact of interventions (clinical practice), or the lack thereof, and to provide evidence and tools that can assist policy makers and healthcare actors in shaping effective policy responses to some of the most prevalent brain disorders.

EUFAMI took part in one of the nine case studies connected to the project, on Schizophrenia. As part of the research activities, user and family representatives were asked to give input the “Patient Journey” to describe how schizophrenia is experienced, from the first awareness of symptoms,

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throughout all stages of the illness. A matrix was developed describing different stages and asking for specific input on each stage (prevention – screening/prodromal phase – early intervention – disease management – disability and rehabilitation – end-stage management and palliative care).

The purpose of this is to show the diversity of real life experiences and to identify key areas for improvement of services and treatment. EUFAMI organized a focus group discussion with family members of persons diagnosed with schizophrenia, to complement the inventory of needs and opportunities composed through a literature review and expert interviews.

About this report

What follows is a family perspective on the journey through services of persons diagnosed with schizophrenia. While not the result of a survey of a representative sample of the population, it does paint a broad, multi-faceted picture of unmet needs and missed opportunities which could and should be tackled to improve the journey of those diagnosed with schizophrenia towards recovery through treatment and services.

To protect their privacy and that of their family members, contributors are referred to with their initials only.

FAMILY MEMBERS:



J from Portugal. Sister to someone diagnosed with paranoid schizophrenia 35 years ago, now in her sixties, who did all the accompaniments being the only sibling.



M from France. Mother of a 36 year old son, first diagnosed 14 years ago, recently re-hospitalised after he had been out of hospital for 4 years.



AD from Belgium. Father to a 38 year old son diagnosed with schizophrenia who has been using services for 15 years. The family's role and involvement has necessarily increased over the years.



E from Portugal. Mother of a son diagnosed with schizophrenia 2,5 years ago. This is her first time in this type of association, which she joined very recently



S from Greece. Brother of a 42 year old sister with intellectual disabilities, diagnosed with schizophrenia about 10 years ago.



C from Malta. Cousin to someone diagnosed with schizophrenia 22 years ago and grandmother to a boy with Asperger's. Mother-in-law to a person with bipolar depression. As a psychiatric nurse she became the go-to person in the family for accompaniments and joined her cousin to numerous appointments with services.

PROFESSIONALS



V from Azores. Psychologist and sister to a brother with severe OCD diagnosed at age 14, now 5 years ago. The first contact with professional services was not with good professionals which she suspects has negatively impacted the course of the disease.



M from Finland. Social scientist with over 10 years of experience working in family organisations in mental health both at national and regional level. Aunt to a 13 year old boy diagnosed with ADHD with severe behavioral symptoms.



AS from Spain. 6 years of experience working with family members in mental health



Facilitator & Rapporteur: Aagje Ieven, Secretary General, EUFAMI

GENERAL COMMENTS:

Asked about their experiences with mental health services in general, participants stated:

M: "It feels the same as 14 years ago. Now they wouldn't dare to turn us away but they still don't treat us as partners. There is no connection with services outside of the hospital, parents are the only link."

AD: "Confidentiality is, in my experience, often used as a curtain to hide one's unwillingness to cooperate with the family members. But health professionals and families have the same aim: to achieve recovery, they should be allies."

The general sentiment amongst participants was that family members nowadays are beginning to be involved in treatment and recovery plans by service providers, though not as much as they should, leading to short term loss in quality of services & quality of life for those using the services - but just as problematically the services do not cover the family members or their needs, which leads to large economic losses on the longer term.

Participants also urged the project researchers to look at the economic impact on all family members. This should include not only the impact on parents (often affecting the caring parent's working ability), but also siblings, who have a bigger, longer journey with their brothers and sisters, who also miss opportunities along the way and who will endure the impact after their parents are gone.

In this particular group no children of persons with schizophrenia were represented but their experiences too should be taken into account.

C: "His daughters did not marry because they were afraid of the illness, that is the kind of impact stigma has on people's lives."

IT STARTS WITH A CRISIS: ACCESS TO SERVICES AS A CROSSCUTTING ISSUE

The general response to the matrix developed to elicit specific input on each stage of life with schizophrenia (prevention, screening/prodromal phase, early intervention, disease management, disability and rehabilitation, palliative phase if relevant) was that the division wasn't extremely helpful.

(M): "The division in stages is perhaps not so relevant from the perspective of a family member. My experiences with services across those stages have been largely the same."

Comparing experiences, the first contact with services was usually not through prevention/screening/early interventions. For almost all family members of someone with schizophrenia their journey "started" with a crisis.

Crisis, stigma and prejudice play a big part in this crisis. Persons hearing voices, experiencing hallucinations, etc. should be seen by medical services rather than be picked up by the police as if they were criminals, which happens all too often. First contact should, moreover, be with a well-informed medical professional with up to date expertise in mental health. Finally, when first contacts are with the police, it's even more difficult than otherwise to make it clear to family members that they're experiencing mental ill health.

The reason many journeys starting with crisis was considered to be the lack of accessibility of services, in each sense of the word.

Families often encountered difficulties in getting the family member experiencing symptoms of psychosis to see a professional because often, they did not realize there was something "wrong".

M: "If doctors or nurses would accept to come home to observe people, that would make it so much easier to get the right support, because what can you do as a parent if your child doesn't want to come to the doctor or hospital?"

You cannot force them. It took us 5 to 10 years to get him a diagnosis and then the right support and I feel this determined his future chances for recovery in a very negative way. Why would they refuse to come to our home? During our most recent crisis, I called a new mobile service for psychiatric emergencies in Paris. We brought the man to my son's room where he had been locking himself up for months. One minute later they came out and my son got into the car with him to go to the hospital. It was a great service, but unfortunately it was also extremely expensive."

J: "The most difficult time for us was one of compulsive internment when the police came. This was really traumatic, and that was only necessary because there was no mobile unit to come to people's homes. Such a unit would be helpful not only at the onset but during the entire process. Rather than burdening families with the task of ensuring their loved one gets to the services, with force if needs be, let professionals come to the home and support families in supporting their loved one. There will be less relapses, the frequency of "episodes" will go down."

It was agreed that we need to move away from the classical model where doctors assume a passive role, sitting within the walls of the service facility, waiting for patients to find them. There was a strong consensus that wide availability of affordable, mobile services could prevent many a crisis and involuntary treatment.

After highlighting these difficulties with the matrix, the group nevertheless decided to try and discuss each stage of life with a diagnosis of schizophrenia in turn

PREVENTION

Schools are a very important place to proactively tackle mental health issues.

The importance of a healthy lifestyle: participating in sports, making friends, participating in social life, needs to be emphasized. Often social isolation starts before other symptoms become very clear. Young people should not have to rely on family members alone for social contact.

C: “If we want to do real prevention we also need to tackle cyberbullying and drug intake.”

Awareness raising in mental health is much needed, still. It’s important for everyone to be able to recognize symptoms early, but also to learn to see mental health in a different way.

Prevention should start before birth. One doctor should be appointed in the beginning of the pregnancy and start prevention there, prenatally, and we should already be working in mental health promotion with children ages 0-3, informing childcarers on infant mental health.

AD: “When by chance I met a doctor present at the birth of our son, who spent 1 month in neonatology, he told me that those children have a higher chance of mental health problems than the average population. The experiences of young children are so important, what happens in their earliest hours is their measure, it stays in the subconscious.”

C: “My cousin was the only surviving baby of a triplet, and had a low birth-weight, before that we had no schizophrenia in the family. It’s been mentioned that this could have been a cause.”

Moving, particularly to a different culture is a risk that needs to be taken into account (applies to students, but also to immigrants/refugees)

PRODROMAL PHASE / SCREENING

If we realistically want to catch prodromal symptoms sooner, we need more psychologists at school. Teachers will often notice something’s wrong before parents do but do not have the tools to support, and there will be no followup, no preventive action, it’s not taken seriously. Educational staff and social workers need to be trained to recognize symptoms and stronger integration and follow-up are needed.

M: “When my son was 11, one of the teachers alerted the family that he ‘had problems’ and needed to see a psychiatrist. He went for six months. At the end he did not want to continue. We never thought it was so serious, we thought the psychiatrist would have solved whatever was wrong. We only realized how serious it was when we got a phone call from the police more than ten years later.”

Primary carers such as GP’s, nurses, childcarers, need to be better educated in mental health. GP’s in particular need to know as much about mental health as they do about diabetes, HIV, and cancer, etc., so that they can recognize mental health problems better. This is an issue of parity of esteem and parity of investment.

EARLY INTERVENTION

The first obstacle is inside the family: strong resistance to acknowledging and tackling the problem – the first reaction in families is often denial and this goes more so for men than for women, participants felt. Stigma is a big risk factor. Again it was stressed how much awareness raising is needed.

J: “30 years ago it was almost impossible to get a diagnosis for my sister, the stigma was so much worse than today, people didn’t talk about the subject, they were ashamed, they didn’t recognize mental health problems. The four years it took (ages 22 to 26) to get a diagnosis for my sister were a nightmare for her and for the entire family. Our parents put their own lives to a complete stop. I was 15 years old at the time and I was the one to accompany my sister to the hospital on all of her appointments.”

There is an issue with access to quality services, families don’t always have the information, knowledge or opportunity to choose a good service provider (and ideally of course there should be no bad ones):

V: “One problem in mental health services in general is that the quality of services is too variable. My brother was very different at the beginning, much better, than he is now. We had a bad psychologist: he told my parents my brother needed more discipline, but this worsened his OCD symptoms. When I started studying psychology I felt I couldn’t do much to help out at home but then I researched better psychologists who were aware of the latest insights in psychiatry. Now we have a psychiatrist/psychologist team and the psychologist is very available, we can call if there’s a problem and he answers our phone calls. My brother also gets better medication for his problem now.”

S: “It took too much time to find good professionals. Mental health needs a multidisciplinary team of professionals working closely together who see the patient and the family as active participants”

V: “When we searched for help, my brother suffered very much – he isolated himself from friends, and didn’t talk to us. But communication is the basis.”

Family organisations can and do play an important role in this, but are not always existent or properly financially supported:

AS: “For many families organisations like ours, and our family help and chat-lines, are the first go-to source of support when they notice symptoms. It needs to be recognized that family organisations are also part of the service landscape and do give real support to these people who do not know where to go or how to communicate with their family member”

The range of services and treatment options is sometimes too narrow, or one-sided:

E: “ Psychological counseling services at the hospital were almost non existent and certainly not sufficient. They used psychology to do the diagnosis but nothing followed in terms of psychological support. The treatment plan was based solely on medication.”

M: “The medical approach is not enough. We need a stronger social approach at every level, from research to support services, I would say more social scientists at every level. I want to stress the importance of a holistic approach. Mental health problems also exist in the space between persons, they are interpersonal problems to an extent, they exist and wreak havoc in the family and a good approach tackles not only the biological but also the interpersonal aspects of it. We need to insert the “family approach” into the very way the services are structured, make it a mandatory box to tick or question to answer in standard questionnaires, put the family aspect in the software that collects that data on mental health.”

Communication with family members is key, they need to be heard extensively in this phase. They can give the family history. They need to be given time to talk about what they have noticed as alarming and strange which a doctor may not ask about but which they know is unusual for this child; they also need to be given time to talk extensively about their experiences with the child broadly because some of what they experience they may not recognize as symptoms while a doctor will.

Good communication between professionals is very important as well. It was remarked that it would be important to involve any professionals well acquainted with the young person.

PLANNING FOR RECOVERY

We prefer the term “planning for recovery” to “disease management” and “disability and rehabilitation”

By recovery we mean: working, included in society, having a meaningful life with joyful experiences

We need team instead of individual appointments. It is a complex disease and you get different appointments with different health providers which places a high burden on the patient/ family and each provider sees only their facet. Also, medication alone doesn't cure it. Psychosocial support is always needed.

E: “Lines of communication often only operate vertically. It's not normal that there is so little horizontal communication between professionals, and that the person or their family is responsible for all these lines of communication.”

Family members need to be integrated in such care teams. Family members sharing their day-to-day experiences would bring a different vision to such teams. They should be represented on the teams.

M: “When my son went to the psychologist at 11 we asked would he talk to us. Because of confidentiality he did not want to, and also did not ask the teacher what they saw that was so alarming. He did not work as a team for my son. There is no place for teachers in this system.”

We need to improve communication between psychiatrists, families, schools and teachers. **A teacher could be part of the care team.**

There also needs to be a contact in the professional team that the family members can call for assistance.

C: “Relatives should be listened to right away and there needs to be some place they can call for immediate assistance. People should not have to wait for the next appointment. Only then can we properly prevent relapse and more damage.”

We should be careful not to miss an important point: as symptoms become “manageable”, high blood pressure and diabetes develop as a side effect of medication – it's a knife cutting from both ends. **People should be able to make informed choices, and have quality options to choose from according to their needs.** Quality of life is important.

J: “The medication was much stronger than today. So were the side effects. The periods of crisis were longer. Probably, if the medication of the past had not been that heavy it would not have compromised her life so much, and so much of her life would have been lighter. And if they would have had the reference therapist at the hospital, working with families in follow-up phases after discharge, that would have been better. Home visitors would help families. And we need community services.”

Need for **free legal aid for persons** with ongoing problems: economic consequences of not being able to work leads to the risk of homelessness and re-institutionalisation in prisons.

AGEING (not exactly “end-stage management and palliative care”, but questions arise as patients age and may not be able to rely on their primary carer anymore)

On average, persons diagnosed with schizophrenia die 20 years younger, attributable to physical comorbidities – without taking into account the high risk of suicide.

Services for older persons with mental ill health in the community are non-existent in many countries.

S: “My sister is lately not too strong physically and is experiencing trembling as a side effect of her medication. I worry about her future when our mother cannot care for her and there will be no system that can provide care for her.”

J: “30 years have passed and it looks like my sister, as she ages, will need to be re-institutionalised, because of the structures. We don’t have structures in communities, professionals who can support her at home. We have no choice.”

CONCLUDING REMARKS

Finally, we asked all contributors “If there was one moment in the course of your family member’s Journey through services that you could go back to and change, what would it be? Where was an important opportunity for recovery missed?”

M: “Doctors or nurses would accept to come into our home to observe. It took us 5 to 10 years to get him a diagnosis and then the right support and I feel this determined his future chances for recovery in a very negative way.”

S: “It took too much time to find good professionals. Mental health needs a multidisciplinary team of professionals working closely together who see the patient and the family as active participants”

V: “If we, doctors, teachers, nurses, people experience mental ill health and their family members, all treat each other like human beings, with dignity and mutual respect, that would already change everything.”

AS: “I would like to reiterate an idea suggested by our former President: if I could change something I would set a quota for financial support to family associations. For many families organisations like ours, and our family help and chatlines, are the first go-to source of support when they notice symptoms. It needs to be recognized that family organisations are also part of the service landscape and do give real support to these people who do not know where to go. Policymakers and other professionals should know we exist, that we try to direct family members to the correct services, and should direct them to us if they need us. Services that family organisations provide should exist everywhere, which is currently not the case.”

M: “The medical approach is not enough. We need a stronger social approach at every level, from research to support services, I would say more social scientists at every level. I want to stress the importance of a holistic approach. Mental health problems also exist in the space between persons, they are interpersonal problems to an extent, they exist and wreak havoc in the family and a good approach tackles not only the biological but also the interpersonal aspects of it. We need to insert the “family approach” into the very way the services are structured, make it a mandatory box to tick or question to answer in standard questionnaires, put the family aspect in the software that collects that data on mental health.”

C: “Relatives should be listened to right away and there needs to be some place they can call for immediate assistance. People should not have to wait for the next appointment. Only then can we properly prevent relapse and more damage.”

E: “In the services, the lines of communication often only operate vertically. It’s not normal that there is so little horizontal communication between professionals, and that the person or their family is responsible for all these lines of communication.”

AD: “Confidentiality is still a problem. Psychiatrists don’t share enough information with families. And I would want to see prevention from an early age. The experiences of young children are so important, what happens in their earliest hours is their measure, it stays in the subconscious.”

J: “The diagnosis should have been earlier. My sister graduated when she was 22, that’s when it all started and it took from age 22 to age 26 to get the diagnosis. These four years were a nightmare for her and for the entire family. Our parents put their own lives to a complete stop. I was 15 years old at the time and I was the one to accompany my sister to the hospital on all of her appointments. Probably, if the medication of the past had not been that heavy it would not have compromised her life so much, and so much of her life would have been lighter. And if they would have had the reference therapist at the hospital, working with families in followup phases after discharge, that would have been better. Home visitors would help families. And we need community services.”

POLICY RECOMMENDATIONS:

EUFAMI advocates for:

Accessible, affordable community services, including

- investment in affordable community based mobile services which can visit persons with mental ill health in their family home to prevent crisis and involuntary treatment.
- availability of a wide range of services combining treatment and/or psychosocial support with physical health care, social and economic support, legal aid etc. through team appointments, and which include users and family carers as active participants in the care team

- family support organisations are a part of the service landscape and need to be invested in
- community based services for older people with severe mental ill health

Involvement of and good communications with family members from the first contact with services, in planning for recovery, treatment and care should be the standard, not involving them the exception in cases where it’s not in the user’s best interest.

Parity of investment in mental health, at a level with physical health – including investment organisations and policies providing support to informal/family carers in mental health to prevent burn-out, health problems and economic duress.

Mental health prevention in schools, early childcare and primary care services, including mental health on the curriculum of teachers, childcarers and primary carers, and presence of psychologists in schools and primary care settings. Zero tolerance of (cyber)bullying in schools.

Preventive programmes for young people moving away from home for the first time, as well as mental health services for young people on the move.

Preventive programmes and services for children of parents with mental ill health

Awareness raising against stigma