DUTCH
SAFETY BOARD

# Summary

# Care for safety

## Safety of persons with a serious mental illness and their environment

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## The Dutch Safety Board

When accidents or disasters happen, the Dutch Safety Board investigates how it was possible for these to occur, with the aim of learning lessons for the future and, ultimately, improving safety in the Netherlands. The Safety Board is independent and is free to decide which incidents to investigate. In particular, it focuses on situations in which people's personal safety is dependent on third parties, such as the government or companies. In certain cases the Board is under an obligation to carry out an investigation. Its investigations do not address issues of blame or liability.


**Dutch Safety Board**

Chairman: T.H.J. Joustra
M.B.A. van Asselt
S. Zouridis

Secretary Director: C.A.J.F. Verheij

Visiting address: Lange Voorhout 9
2514 EA The Hague
The Netherlands

Postal address: PO Box 95404
2509 CK The Hague
The Netherlands

Telephone: +31 (0)70 333 7000

Website: safetyboard.nl
E-mail: info@safetyboard.nl


N.B. The full report is published in the Dutch language. If there is a difference in interpretation between the Dutch report and English summary, the Dutch text wil prevail.

# CONTENT

# SUMMARY

Individuals suffering from serious mental illness (SMI) can end up in unsafe, sometimes lethal situations. The stories of Sven, Jasper and Nicky are distressing examples.

Sven is a young man who stands out because of his distracted behaviour. He grabs people on the street and tells them the world is falling apart. Talking with a psychiatrist does not lead to treatment because Sven does not want any treatment. When Sven tries to commit suicide at home by dousing himself with petrol and opening the gas valve, all the surrounding houses are evacuated because of the explosion hazard. Sven is subsequently committed for treatment. After the treatment, social services lose track of him because he travels abroad. After his return social services do not become involved, despite the efforts of an involved police officer. In the end he takes the lives of his girlfriend and himself.

Jasper is a single young man who lives with his mother most of the time. He has anger attacks and psychoses, and is diagnosed with an autism spectrum disorder and paranoid schizophrenia. This diagnosis will be revised later. Jasper is committed several times for treatment. Because of problems at home and at work, divergent diagnoses and substance abuse, he has to deal with many different mental health and social workers. It is not possible to give Jasper the care that he needs, so he keeps ending up in unsafe situations. He starts a fire in his room, and gets arrested for that. Only after many years suitable placement is found for Jasper, where he gets the care and support he needs to redirect his life.

Nicky is a single woman with a paranoid personality disorder and psychosocial issues, as well as problems with her environment and housing situation. She is under voluntary outpatient treatment by a psychiatrist, and visits the day centre twice a week. The crisis services for emergency mental health assistance and a specialised social services team are involved. However, because of a lack of clear and concrete agreements, each party thinks that the other party was assuming the coordination responsibilities for mental health and social services. At some point mental health and social workers lose track of Nicky. A neighbour ends up finding her at her home, in a very confused state. She dies shortly afterwards at the emergency department of a hospital.

In the Netherlands there are 250,000 to 300,000 persons with a serious mental illness (SMI). Between 10,000 and 20,000 of them need acute care because of their condition. The problems of vulnerable persons with an SMI are often chronic, multiple and episodic. In the course of their lives they have had a variety of new and recurring psychiatric issues for shorter or longer periods of time. There may be occasional recovery in-between, but this tends to be fragile. In many cases there is a concurrence of problems related to housing,

finances, relationships, work and how their days are spent. In addition, some of these people have serious health problems, such as addictions and the related physical conditions. Because of their disorder, moreover, they are not always capable of asking for help, or will just avoid mental health and social services. The care needs of persons with an SMI are complex and difficult to predict. These individuals are very dependent on their loved ones and on various mental health and social workers, who have to collaborate closely. This dependence makes people with an SMI vulnerable. Not getting the care and help they need can lead to unsafe and even life-threatening situations for themselves as well as for those around them.

This investigation was motivated by indications of the increasing number of unsafe situations around persons with an SMI. The Dutch Safety Board investigated the factors that contribute to the development of unsafe situations for persons with an SMI and their environment. The goal of this investigation is to provide insight into how the safety of vulnerable persons with an SMI and their environment can be increased.

**Cases**

To gain further insight into the nature, complexity and diversity of the problems, the Board investigated, among others, seven cases where safety is at risk. These cases present poignant examples of unsafe situations persons with an SMI can end up in. Relatives and social workers often make numerous attempts to have these individuals treated, give them medication and offer them support – voluntarily or otherwise – so that they can lead a somewhat normal life. A complicating factor is that their condition can make persons with an SMI get themselves into further trouble. There are distressing situations that escalate to a life-threatening level despite the involvement of relatives as well as mental health and social services, making vigorous intervention by the police unavoidable. Reality also presents intense dilemmas for mental health and social services, such as situations of self-neglect where the right of self-determination can clash with the right to receive good care. Some cases demonstrate that neither relatives nor the involvement of mental health and social services could prevent a person from dying from the direct or indirect consequences of their serious mental illness.

The cases illustrate the urgent need for adequate care for persons with an SMI. This is not only in the interest of their own safety but also in that of their environment. To gain access to adequate care, establishing a diagnosis seems a self-evident precondition, yet sometimes patients need care and help before a diagnosis can be made. The mental health and social services system is not equipped for this though – certainly in the case of complex conditions, like psychotic illness combined with a narcotics addiction.

The complex care needs of persons with an SMI make high demands from all those involved, and it is not always realistic to expect any, much less full recovery. Many mental health and social workers do their very best, but the way their work is currently organised does not always help. Sometimes the way the system is set up even aggravates the problems of individuals with serious mental illness, and that also increases the safety risks for themselves and others. Practice shows that there still remain safety gains to be achieved, primarily for patients themselves but also for their environment. The Dutch Safety Board sees three important focal points in this context: access to adequate care, identification of safety risks, and the ability to act of mental health and social workers.

**Access to adequate care**

Assessing the care needs of persons with an SMI can be a lengthy and complex process. In addition to mental health services (in Dutch: ggz), they also tend to need help with housing, finances, relationships, work and the way they spend their days. Once the care needs are clear, it can still take a long time before patients with an SMI actually get the care they need. Neither the legal framework nor the financing structures for care and support are designed to offer the multiple care and help that persons with an SMI are in need of. Care based on the Long-Term Care Act (in Dutch: Wlz) is practically impossible to get for this group, and because of financial considerations many healthcare providers focus primarily on the short-term treatment of patients with simple problems. Waiting times for the ggz and protected living, a lack of trained personnel and regulated exclusion criteria hinder the access of persons with an SMI to adequate care.

The investigation shows that nowadays in cases of escalation the attention focuses on crisis stabilisation, hence neglecting the continuity in care needed before and after. Underlying problems are therefore tackled to a limited degree and the patient is not really helped in the long term. This puts undue pressure on relatives and others directly involved. Sometimes there is no other option than involuntary commitment of SMI patients. This may help temporarily but can also aggravate problems, for instance due to a loss of income and/or housing. Patients with an SMI have no or very limited options for more adequate care though. Right now, outpatient care and social facilities do not always meet the care needs of all SMI patients.

**Identification of safety risks and exchange of information**

Mental health and social workers can lack a perspective on safety risks. These include both patient safety and the safety of people in their environment, such as relatives, neighbours and care providers. Involved parties, such as the ggz, municipalities and the police, assess the safety or unsafety of situations from different perspectives. The safety perspective is determined one-sidedly by the party directly involved at that moment. In addition, patient data is recorded in different systems across multiple agencies and organisations. This results in fragmented information, incomplete patient records and limitations in access to information. Because mental health and social workers essentially control access to the available information themselves, they are largely dependent on each other's authorisations, availability and effort in order to share the information needed to secure adequate care and safety. As a consequence, not all safety risks are identified and managed on time.

The perspective on safety risks is further limited by insufficient access to information. Initiatives to improve access to information are in a premature stage or focus more on providing access to information between patients and their care providers than on providing access to information between mental health workers and social workers. In addition, mental health and social workers do not make enough use of the leeway that professional confidentiality allows for when it comes to sharing information. Professional groups, institutions and care providers place a one-sided emphasis on not being allowed to share information. This causes care providers to insufficiently explore the possibilities with regard to asking patients for permission to share information, supporting other involved parties in their action perspective and sharing information based on their duty of care when this is in the interest of the patient.

**Mental health and social workers' ability to act**

The emphasis on following rules and protocols does not relate well to the multiple and episodic care needs of these individuals. As a result, mental health and social workers experience limited professional latitude to deliver the needed personalised care to persons with an SMI. The provided care thus fits their care needs only to a limited degree. This issue is amplified by the dilemmas that mental health and social workers are faced with. They have to consider a variety of interests and values, such as the right to adequate care, patients' right to self-determination, protection of the professional confidentiality and the safety of patients, their loved ones and care providers. As these interests and values cannot always be reconciled, mental health and social workers are sometimes hesitant to act. This increases the chance of their actions being led by regulatory frameworks rather than the patient's care needs and the necessity to manage the various safety risks in mutual collaboration.

Coordination problems between the involved parties inhibit a joint approach of mental health and social services towards persons with an SMI. Despite good intentions, it is not self-evident that parties are proactively exchanging knowledge, information and expertise. For this reason, mental health and social services' abilities to act cannot be optimally deployed. In addition, multiple views and ambiguities about the roles of the involved parties delay the actions of the care network.

**Final words**

The ability to prevent persons with an SMI and their environment from ending up in unsafe situations makes high demands from the mental health and social workers tasked with helping this group. Despite the efforts and involvement of the tasked parties, the safety of both persons with an SMI and their environment is at present insufficiently secured. To improve this, it is necessary for care and support services to properly meet the multiple and episodic care needs of patients. Financial restrictions in the legal regulations should be removed for persons with an SMI. Mental health and social workers also need to take more advantage of their professional latitude to secure the safety of persons with an SMI and their environment. This requires professional groups, institutions and care professionals from the various domains to coordinate how to identify, exchange and manage safety risks at an early stage, as well as recognise and openly discuss dilemmas that compromise the safety of patients and their environment. Mental health and social workers should also be supported to a greater extent in their ability to become responsible for offering personalised care to individuals with an SMI. To this end, it is necessary to make it easier for mental health and social workers to accumulate sufficient knowledge and skills, to assist them in dealing with dilemmas and to structure the preconditions for them to want to, be able to and dare to offer personalised services.

# CONSIDERATION

The Dutch Safety Board has observed that the system of care and support for persons with a serious mental illness (SMI) is currently insufficiently equipped to prevent unsafe situations. The system does not take the limited self-reliance of persons with an SMI and their fluctuating care needs sufficiently into account. Because of a fragmentation of tasks and responsibilities, complex financing structures and a cumbersome bureaucracy, it is a nearly impossible task to organise the needed care and support in all cases, primarily for persons with an SMI but also for their care providers.

Vulnerable persons with an SMI may, at different moments in their lives, end up having to deal with problems in different life areas, such as housing, finances, relationships, work and the way they spend their days. If the care they need does not arrive or comes too late, the problems may accumulate and worsen to such a degree that they escalate, posing a safety risk. Such escalations, which can be life-threatening, make society react intensely, as people don't always know how to respond to the situation and fear sometimes wins over understanding.

For their care and safety, people with an SMI depend on their loved ones and professionals from different domains who have to work closely with each other. This requires a high degree of effort and involvement from professionals. It also requires an adequate structuring of the system that has to facilitate the multiple care and support needs for the different life areas. And yet, the approach to the complex problems of vulnerable persons with an SMI is currently taking place from a fragmented system made up of many different mental health and social workers, institutions, supporting organisations, domains, legal regulations and complex sources of financing.

Because of this fragmented system, in complex situations the focal point is not the person with an SMI but the organisation offering the care. In many cases, each separate problem is processed by a different mental health worker or social worker, both consecutively or simultaneously. This does not allow enough of a focus on the connection between the problems and care needs of persons with an SMI, and on the fact that the nature and intensity of their care needs may fluctuate strongly. As a result, mental health and social workers are not always able to meet the care needs of individual patients. Besides, it is not always possible to clearly ascertain which care fits the specific situation of the patient. Mental health and social workers are regularly confronted with intense dilemmas where different and possibly conflicting values – such as the right to self-determination, adequate care, and the safety of patients, their loved ones and care providers – are at stake.

The multiple and episodic problems of vulnerable persons with an SMI do not relate well to an approach from defined domains, multiple financing sources and a strict interpretation of rules and procedures. They ask for a joint approach in which mental health and social workers constantly and jointly search for the best way to deal with a given situation. This requires intensive coordination between all parties involved in the care and support of vulnerable persons with an SMI. With patient participation in mind, the involved parties delegate the steering of the mental health and social services to the patient as much as possible. But because of their mental disorder these individuals are not always able to take the reins of their situation. This is particularly relevant at those moments when the required care is urgently needed and there are safety risks.

The investigation shows that the distressing situations of persons with an SMI also unleash feelings of powerlessness and frustration in the involved professionals. The experienced lack of control over the situation often translates into a reflex to follow the rules, as a footing is sought in procedures and protocols. The Dutch Safety Board does note that when problems escalate it generally isn't because rules were ignored or absent. On the contrary, it is precisely the strict interpretation of and adherence to rules, procedures and protocols – for example out of fear of disciplinary action – which hinders professionals from fully using the leeway they have to help the patient. The multiple and episodic problems of vulnerable persons with an SMI require professionals involved in patient care and support from different domains to know each other and to know how to connect. They should also be able to make use of the different perspectives of the patients, their loved ones and experts, respectively.

The Dutch Safety Board acknowledges that there are many ambitions and good initiatives to arrive at better collaboration in the interest of persons with an SMI. A variety of examples show that it is possible to make patients, their loved ones and experts more involved in the care and support, to openly discuss dilemmas related to care and support, to stimulate peer review and joint learning and to make decisions aimed at providing adequate care and support in the interest of the patient. The fragmented way in which the care and support system is currently organised, based on varying regulations, is often an obstacle to these goals.

More is needed than just good intentions to make individual patients the focal point from which to manage their safety and that of their environment. Safety as part of adequate care requires professionals who are able to make optimal use of their ability to act, organisations that think and act in the interest of the patient, and a system that facilitates rather than stands in the way of care and support for vulnerable persons with an SMI.

# RECOMMENDATIONS

The government, mental health services (ggz), advocacy organisations and health insurers are currently working on a wide structural improvement of the care and support for persons with an SMI. In July 2018 a global agreement was signed for the entire ggz that included arrangements to offer people the mental health care that they require, adapted to their individual needs. Additionally, the Forensic Care Act was implemented on 1 January 2019 and the Dutch Mandatory Mental Healthcare Act (Wvggz) and the Care and Compulsion Act (in Dutch: Wet zorg en dwang) will be implemented on 1 January 2020. The ggz and forensic care will further be working with a new product structure starting in 2020, and the Long-Term Care Act (in Dutch: Wet langdurige zorg) is expected to be open to persons with psychiatric disorders in 2021. Various collaborative partnerships are working on development and implementation projects to improve the care and support for persons with an SMI. Their goal is to offer patients the care and support that fits with their care needs at the right moment.

The Dutch Safety Board considers it important for the involved parties to follow the recommendations by joining the ongoing initiatives for improvement. Improving the safety of persons with an SMI and their environment requires an approach that is tailored to the specific care and support needs of these persons. To that end, it is necessary for all involved parties from the various domains to pull together in order to secure effective care and support within the system.

To be able to structurally offer adequate and safe care to persons with an SMI that fits their multiple care needs, specific arrangements are necessary. The Board recommends the following.

*To the Minister and State Secretary for Health, Welfare and Sport:*

In addition to the GGZ General Agreement, arrive at an agreement specifically aimed at offering care and help to persons with an SMI. This must lead to a cohesive provision of care that closely meets the needs of persons with an SMI for multiple, episodic care and support in different life terrains.

The following parties should sign the agreement: patient advocacy groups, ggz facilities, municipalities, the police and health insurers. The following measures in the areas of financing, information exchange and practical authority should definitely be part of this agreement.

**Financing**

Providing adequate care and support to persons with an SMI is expensive, and the compensation given to organisations from a variety of financing sources is insufficient and inefficient. To provide adequate care and support it is important for parties to disburse for their provided services from one single budget.

- Make one single integral budget available for vulnerable persons with an SMI from which all care and support is paid.
- In coordination with the Dutch Healthcare Authority, ensure that the costs can be justified afterwards, so that professionals can offer immediate help and support.
- Remunerate the costs for multidisciplinary coordination and collaboration, consultation with relatives, and joint learning about incidents.

**Information exchange**

To minimise the chances of unsafe situations for persons with an SMI, it is necessary for parties to discuss safety risks at an early stage, for information about the patient to be clearly accessible to those authorised and for professionals to make the best use of their latitude to share information. Adequate exchange of information also contributes to a preventive system in which individuals with an SMI can receive personalised help sooner.

- Make sure that mental health workers and social workers coordinate with each other about the various safety risks early on.
- Try out working from one single, clear dossier for help and services for persons with an SMI.
- Generate more attention for the sharing of patient-related information based on the "conflict of duties", "good practice" and "vital importance" criteria.

**Ability to act**

Vulnerable persons with an SMI need care and support in multiple life areas. This requires a form of collaboration that transcends domains and that is oriented towards multiple care and support of patients. In order to achieve this, parties need to get better at connecting and develop a multidisciplinary philosophy in which care and support for patients is jointly shaped and agreements are made about who is leading what and when.

- Strengthen local care and support services by reducing the caseload of FACT teams. Staff can work with a more local orientation using the same tools, in this way fostering mutual collaboration and coordination between parties.
- Require and facilitate parties' multidisciplinary evaluations and learning from incidents, in order to develop greater insight into each other's needs and possibilities for collaboration.
- Strengthen the position of relatives within voluntary care and support trajectories, as is now arranged for within the Mandatory Mental Healthcare Act.
- Make sure that the announced 24/7 hotline to request help and support for concerns about behaviour related to psychiatric issues becomes operational in the short term.

# CONCLUSIONS

The Dutch Safety Board has observed that unsafe situations for persons with an SMI and their environment occur frequently. This is why the Board investigated which factors contribute to the development of such situations. The Board has concluded that the safety of both vulnerable persons with an SMI and their environment is insufficiently secured. Among other reasons, this is because the care and services provided to this group of people does not meet their care needs sufficiently. Vulnerable persons with an SMI also tend to have problems with their relationships, housing, finances, work and physical health. These problems are largely episodic in nature. This makes them dependent on their social environment as well as on mental health and social workers at different moments, in different life areas and to varying degrees. Because of their mental disorder these individuals are not able to effectively take the reins of their situation. When they cannot take care of themselves, for example during a crisis, someone else needs to protect them and take over these responsibilities from them.

When persons with an SMI do not receive the care and support they are dependent on, their problems can worsen and lead to unsafe situations. It is therefore extremely important to adequately link the care and support to the needs of individual patients. The investigation has shown that the care needed by persons with an SMI is not always provided.

A first important reason the needed care is not provided is that current laws and regulations for care and support are not oriented towards the complex care needs as they present themselves for persons with an SMI. For example, the purchasing price of mental health care is an average price, which makes it cost-ineffective for medical professionals to provide the complex and therefore expensive care needed by patients with an SMI. On top of that, various financing sources for care and support are mutually exclusive. For example, individuals with an SMI have no access to the Long-Term Care Act so they are only eligible for short-term treatment, whereas they tend to be dependent on care and support for a large part of their lives. In addition, the ambition to keep care affordable puts pressure on the purchasing price for healthcare providers, thus fostering specialisation. Such specialisation does not fit well with the multiple care needs of patients. Lastly, waiting times for the ggz as well as protective living delay the providing of adequate care, thus increasing safety risks for patients as well as their environment.

A second important reason why the needed care is not provided is that mental health and social workers lack sufficient perspective on safety risks. The ggz, municipalities and the police each assess the safety of a situation differently. Because they barely explore their perspectives jointly or interrelate them, the safety perspective is determined one-sidedly by the party directly involved at that moment. In addition, patient data is recorded in different systems by multiple institutions and organisations. This results in a fragmentation of information, incomplete patient records and delayed access to the information that is needed to offer adequate care and to secure the safety of patients and their environment.

The perspective on safety risks is further limited because mental health and social workers do not make enough use of the latitude that professional confidentiality allows for when it comes to sharing information. Professional groups, institutions and care providers place a one-sided emphasis on not being allowed to share information. Because of this, care providers inadequately explore possibilities to ask patients for permission to share information, to support other involved parties in their abilities to act and to share information based on their duty of care when it is in the interest of the patient.

A third important reason the needed care is not provided to persons with an SMI is that mental health and social workers experience limited professional latitude to provide the care that is needed. The emphasis on following rules and protocols in the care for and support of vulnerable persons with an SMI does not relate well to the multiple and episodic care needs of these individuals. Due to the lack of professional latitude experienced, mental health and social workers may have reservations about providing personalised care to individuals with an SMI, so the care given ends up not fitting the patient's needs. The experienced lack of professional latitude is enhanced by the dilemmas that mental health and social workers are confronted with when caring for persons with an SMI. Because a variety of values are at risk that can be in conflict with each other – such as the right to adequate care, patients' self-determination, protection of patient confidentiality, and the safety of patients, their loved ones and care providers – mental health and social workers may be hesitant to act. As a result, their actions may end up being guided by regulatory frameworks instead of by the care needs of individual patients. This can increase safety risks and lower their manageability.

To increase the safety of persons with an SMI and their environment, it is necessary for the care and support to fit with the complex and episodic care needs of individual patients. To this end, financial restrictions in laws and regulations should be removed. This can be done by widening access to existing financing resources, such as opening the Long-Term Care Act to vulnerable persons with an SMI, as well as by experimenting with new, domain-transcending financing resources. Mental health and social workers also need to take more advantage of their professional latitude to secure the safety of persons with an SMI and their environment. This requires that professional groups, institutions and care professionals from the various domains discuss how to detect, exchange and manage safety risks earlier, as well as recognise and openly discuss dilemmas that affect the safety of patients and their environment. Lastly, mental health and social workers should also be supported to a greater extent in their ability to take responsibility for offering personalised care to individuals with an SMI. To this end, it is necessary to make it easier for mental health and social workers to accumulate sufficient knowledge and skills, to assist them in dealing with dilemmas and to structure the preconditions for them to want to, be able to and dare to offer personalised services.

DUTCH
SAFETY BOARD

**Visiting address**
Lange Voorhout 9
2514 EA The Hague
T 070 333 70 00
F 070 333 70 77

**Postal address**
PO Box 95404
2509 CK The Hague

www.safetyboard.nl