

# **Advocacy for psychiatric patients in the Netherlands. The model of the Dutch National Foundation of Patient Advocates in Mental Health Care**

## **Defensa de los pacientes psiquiátricos en los Países Bajos. El modelo de la Fundación Nacional Holandesa de Defensores del Paciente en el Cuidado de la Salud Mental**

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### **Abstract**

In the Netherlands, involuntary as well as voluntary psychiatric patients have a right to individual support of a patient advocate. Since 1982, the support of patient advocates has been organized and facilitated by the Dutch National Foundation of Patient Advocates in Mental Health Care. The way in which patient advocates have to perform their statutory tasks has been elaborated in rules of conduct formulated by the above-mentioned Foundation. Some cornerstones in the Dutch model are independence from the psychiatric hospital, easy accessibility, confidentiality, receptivity to a patient's questions and complaints, an orientation to the individual patient's legal position, partiality, promotion of the patient's health care-related interests as the patient perceives them, and

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the requirement of patient assent for actions of the patient advocate. The combination of these cornerstones results in a very specific role for the patient advocate. Presupposed by the Dutch model is both a good fit of this role with the roles of other actors in the health care system, and just health laws. The value of such patient advocacy depends on the degree to which these two presuppositions are fulfilled. Critical questions can be raised in relation to the fit at issue and to the quality of positive law.

*Keywords:* mental health, patient advocacy, medical legislation, medical ethics.

## Introduction

The possibility of declaring patients incompetent, of resorting to substitute decision-making arrangements for the patient, and of involuntary treatments characterize psychiatric practice more than most other fields in medicine. Thus, conflict, power, the risk of its misuse, and a possible imbalance of power are inherent in psychiatric care. The introduction of new psycho-pharmacological drugs since the 1950's increased the number of treatment options, but it also involved considerable, sometimes serious, adverse side effects, which aroused resistance against such psychiatric treatments. The anti-psychiatry spirit of the age led to a growing importance being attached to the idea of legal protection and to the idea that review of drastic decisions affecting the life of psychiatric patients might sometimes be necessary. Against this background, the Dutch National Foundation of Patient Advocates in Mental Health Care (hereafter: the Dutch National Foundation) was formed in 1981, its Dutch name being «Stichting PVPGGZ», where «pvp» stands for «patiëntenvertrouwenspersoon». A literal translation of the latter term into English would be 'patient confidentiality person'. This paper translates it as 'patient advocate'.

In 1982, the first patient advocates started their activities in psychiatric hospitals on an experimental basis. In 1994, a new statute dealing with involuntary treatments in psychiatry (i.e., Special Admissions into Psychiatric Hospitals Act) came into force. With that new statute, the figure of the patient advocate acquired an explicit statutory basis. Initially the statutory duty to provide the assistance of a patient advocate only applied to the area of psychiatry, where patient advocates have been active for 37 years now. These days, the patient advocacy service is also being developed for the areas of psychogeriatric care and care of persons with intellectual and developmental disabilities, mainly by institutions other than the Dutch National Foundation. Advocates in these areas are called client advocates (in Dutch: «cliëntenvertrouwenspersonen») instead of patient advocates. The provision of client advocacy will be mandatory by law only recently, since January 1, 2020.

In this paper we will first describe the Dutch model of patient advocacy in psychiatry, paying attention to the function of the patient advocate and to the Dutch National Foundation. After that, we offer some reflections on the Dutch model. More specifically, we zoom in on the patient advocate's role in relation to the roles of other actors within the healthcare system, and on the significance of the quality of positive law for patient advocacy according to the Dutch model.

## **1. The Dutch model of patient advocacy in psychiatry**

A patient advocate can inform, advise and support psychiatric patients when they have questions or complaints regarding behaviours or decisions of the psychiatric hospital or its workers towards them. Hence the service of patient advocates is limited to health care-related matters. The rules of conduct of the Dutch National Foundation («gedragsregels pvp») form the core document that defines the function of the patient advocate in psychia-

try. This function will be sketched in terms of its distinctive cornerstones. Also, a brief impression will be given of the organization, structure and activities of the Dutch National Foundation.

*a) The function of the patient advocate*

Eight cornerstones typify the function of the patient advocate in psychiatry according to the Dutch model.

1. *Independence from the psychiatric hospital.* Although patient advocates usually perform their activities in psychiatric hospitals, they are employed by the Dutch National Foundation. Therefore patient advocates need not fear reprisals from the hospital affecting their jobs as a result of their actions, which might be critical of psychiatrists, other healthcare professionals, and hospital administrators.

Boards of psychiatric hospitals may file a complaint about a patient advocate before a special complaint committee (see section 1, b), for more information about this committee). But it is up to the Dutch National Foundation to decide whether or not to attach any consequences to the judgment of this committee.

2. *Easy accessibility.* Patient advocates must be easily accessible for individual psychiatric patients. Ideally there should be no temporal, local, physical, psychological or communicative barriers.

In practice this means that patient advocates usually have a consultation room in the hospital, with office hours. They pay regular visits to wards, even without an appointment with a patient, in order to introduce themselves and to distribute posters, flyers and brochures with contact information. They may also give open information sessions for patients about their services. Patient advocates have a legal right to enter all hospital rooms where patients may sojourn without permission of the hospital. The hospital may not limit contact between patients and their patient advocates. The Dutch National Foundation has a help desk staffed by patient advocates that can be reached by telephone and by e-mail from Mon-

day to Saturday. In addition, on four weekdays, there is an online chat service in the evening hours. Hence, there are several ways for the patient to get into contact with a patient advocate.

3. *Confidentiality.* Patient advocates must observe confidentiality regarding information the patient has shared or that they have gathered. This confidentiality applies not only towards third persons and healthcare professionals, but also towards family members and patient representatives or substitute decision makers when the patient does not have legal capacity. The same goes for legal proceedings. A breach of confidentiality is only admissible in exceptional situations in order to prevent serious harm. A corollary of confidentiality is the principle that the patient advocate should not have more information about the patient than the patient himself. When the patient advocate receives information about the patient from other persons, he ought to share it with the patient.

4. *Receptivity to a patient's questions and complaints.* The patient advocate should be open to any question of a patient that relates to her or his psychiatric care. No formalities are required to address a patient advocate. It does not matter how much time has passed since the behaviour or decision in question took place, nor whether the patient has legal capacity. The patient advocate must respond to any question of the patient, even if it is clearly the outcome of a psychiatric disorder.

The only condition for the patient advocate to provide her or his service to the patient is that the patient should be aware that this service is being provided by a patient advocate, which includes a rough understanding of the nature of this service.

5) *An orientation to the individual patient's legal position.* Prompted by the patient's questions, the patient advocate will inform the patient about his rights that shed light on the questions asked, and possibly help him in realising these rights. As noted earlier, an important limitation here is that the patient advocate's service only concerns issues pertaining to the relationship between the patient, on the one hand, and the psychiatric hospital and its workers, on the

other. The patient advocate merely deals with patient rights. In other words, although questions concerning relations with employers or social security organisations, housing corporations, family members, representatives *et cetera* may be important for the patient's health and health care, answering these questions is not the task of the patient advocate.

The information given by the patient advocate involves both material and formal law. If the patient has a complaint or a request in relation to her or his psychiatric care, the patient advocate will analyse the feasibility of it from a legal viewpoint and suggest possible actions. Practical actions undertaken by the patient advocate usually start on the informal level, e.g., by arranging one or more meetings between the patient and the healthcare professional who is responsible for the action with which the patient is dissatisfied. If such meetings do not take away the patient's discontentment, the strategy might be moved to a more formal level. As soon as the patient plans to raise the matter to the judicial level, the patient advocate has to pass on the case to a solicitor or barrister.

In order to fit in with the normative framework used by other judging bodies (e.g., a complaint committee, the health inspectorate, judges) and to promote uniformity among the patient advocates, patient advocates should take positive law as the basis for their legal support. The patient advocates' personal views about justice and the ethical qualities of law ought not to interfere in their professional assistance. When the law changes, the legal support of patient advocates changes accordingly.

*6. Partiality.* Unlike a mediator who is supposed to be impartial, a patient advocate is always legally partial: she or he always takes the side of the patient. The patient advocate is not there to give legal counsel to healthcare professionals. The patient advocate must try to support the patient's wishes with legal arguments. Within the relationship between patient and patient advocate, the patient advocate will give objective legal information to the patient. This means she or he will also point out to the patient any arguments against

the patient's position. In the event of actions towards others, the patient will usually request that only those facts and arguments that are in favour of his position be put forward by the patient advocate.

The notion of partiality implies that there are several parties. Therefore, it can be asked who the parties are in this situation. One might think that the treating psychiatrist is one of the other parties. Insofar as there are no third parties' interests at stake, the treating psychiatrist, as a professional, has to be guided by the patient's health care-related interests. Both the patient and the treating psychiatrist (or other healthcare professional) aim at fostering the patient's health care-related interests. In that sense, there is only one party, i.e., the patient. However, the patient and the psychiatrist may have different perceptions of the patient's interests: the patient has his own perceptions, whether or not influenced by his psychiatric disorder; the psychiatrist's perception of the patient's interest is fed not only by the patient's perceptions of these interests, but also by other sources, e.g., input of the patient's relatives, medical information, professional standards, advice by members of the treatment team, her or his own judgment of the patient's interests as a professional or as a human being. Hence, the two «parties» really are two sets of perceptions of the same person's interests. The task of the patient advocate is to promote the patient's set of perceptions of his interests. This brings us to the next cornerstone.

*7. Promotion of the patient's health care-related interests as the patient perceives them.* In answering legal questions, the patient advocate must be guided by the questions, goals and wishes expressed by the patient, without judging their merits. If the patient aims at goals that are dictated by her or his psychiatric disorder (e. g. psychotic symptoms), the patient advocate takes them at face value and simply informs the patient about their legal feasibility. When the patient insists on taking steps to further these goals, the patient advocate will support him in doing so, even if they are legally

unfeasible or even possibly harmful to the patient in the patient advocate's personal view. The only boundaries in this regard are constituted by the patient advocate's professional role. The patient advocate is expected not to bring in her or his own notions regarding the patient's best interests.

8. *The requirement of patient assent for actions of the patient advocate.* For any action (e.g., contacting the patient, taking and saving notes of a conversation with the patient, talking to a healthcare professional, accessing the patient's file, being informed by a family member), the patient advocate needs the patient's assent. If the patient assents, the patient advocate can undertake the action. If the patient does not assent, the patient advocate may inform him of the consequences thereof. If the patient then still withholds his assent, the patient advocate will generally refrain from the action, regardless of the consequences.

In sum, the patient advocate can be regarded as a legal instrument in the patient's hands. At the patient's request, he will inform him about his rights in relation to the hospital and its workers. If the patient wishes so, he will unconditionally support him in presenting his wishes and complaints towards the hospital workers, and underpin these wishes and complaints with legal arguments, insofar as this is possible. When other procedural steps are available (e.g., submitting a complaint before a complaint committee), the patient advocate may point them out to the patient and help the patient take these steps.

The combination of the eight cornerstones of the role a patient advocate discussed above, particularly the fifth, sixth and seventh, results in a very specific (or, depending on your view, radical) role for the patient advocate. Such an advocate can engage in this role precisely because she or he does not have any responsibility in decision-making regarding the patient's treatment and care. That responsibility rests with other actors, notably the treating psychiatrist, who are expected to take more factors into account than merely the patient's perceptions of her or his health care, and legal argu-

ments favouring those perceptions. Therefore, the function of the patient advocate could be pictured as being a legal amplifier of the patient's voice within the healthcare system.

*b) The Dutch National Foundation*

The Dutch National Foundation, which organizes the patient advocates' service in psychiatry, is funded by the Ministry of Health, Welfare and Sport. It is the employer of patient advocates throughout the country. In every psychiatric hospital in the Netherlands, one or more patient advocates are active. The rules of conduct already mentioned above, specifying the professional role of the patient advocate, are formulated and updated by the National Foundation.

The Foundation has a national bureau guiding and facilitating the activities of the patient advocates. Among other sections of this bureau is the legal section. One of its tasks is to counsel patient advocates when they encounter cases of a legal complexity that exceeds their knowledge. The foundation has also adopted a regulation instituting an external complaint committee, enabling patients (and some other parties) to get an independent judgment from this committee when they have a complaint about a patient advocate or about the manager of a patient advocate.

Some statistics, taken from the annual report 2018, can give an impression of patient advocates' everyday practice. In that year, there were 55 patient advocates. Most of them (36, i.e. 65%) are women. They received 24,155 questions and complaints. About half of these (56,2%) originated from involuntarily committed patients.

Frequent topics of questions or complaints are compulsory treatment (usually medication), limitations of freedom, treatment in general (defective quality of care, lack of continuity, shortage of permanent care staff) and medical files (getting access to and/or a copy of these files). These topics represent the experience of patients who made use of patient advocates' services. Patient advoca-

tes supported patients in 1,462 procedures before a complaint committee and in 9 procedures before the arbitration board for mental health care.

Nine patients submitted complaints about patient advocates before the external complaint committee instituted by the Dutch National Foundation.

## **2. Reflections on the Dutch model**

In the foregoing we observed the main characteristics of the Dutch model of patient advocacy in psychiatry. This model is characterised by the fact that patient advocates have a very specific legal role, that they and the other actors in the healthcare system are supposed to keep to that role, and that the patient advocate's role is based on positive law.

In what follows, the notion that patient advocates should adhere to their role in the mental healthcare system is subjected to some reflection. In addition to that, we will contemplate a few implications of positive law's being the basis for patient advocacy.

### *a) The patient advocate's role within the mental healthcare system*

How does the patient advocate's role relate to the roles of other actors in the healthcare system? The patient advocate has a legal role in a system that is directed at giving health care. In this respect, it can be regarded as a foreign body in the system. Where most other actors are driven by therapeutic motives, the patient advocate uses a legal approach to solve problems. Therefore, the presence of a patient advocate changes the nature of the game, even if she or he broaches the patient's wishes and complaints in informal ways to the healthcare professionals involved.

The professional support of a patient advocate is, in a way, unconditional, aiming at informing the patient about his rights and

helping him realize them. It can only be like that because the services of other actors (e.g., the psychiatrist in charge of treatment) are not unconditional. The function of the patient advocate within the healthcare system presupposes the presence of other actors with different roles. In order for the healthcare system to function properly, the roles of the various actors around the patient should be balanced mutually, like the cogwheels in a machine. It is equally important that the actors involved actually understand their respective roles and act accordingly.

What actors do we find in the healthcare system, and what roles do they play? First, there are the patient (P) and the treating physician, in psychiatric care usually a psychiatrist (Psia). They have a *therapeutic relationship* and form the core of the health care system.

The psychiatrist is often part of a *treatment team*, whose other members might include nurses (N), a psychologist (Pslo) and a *locum tenens* (LT).

The *patient system*, besides the patient, can consist of a life partner (LP), a «contact person» (CP) who arranges practical matters relating to the patient's stay in the hospital, and one or more relatives (R). In addition, the patient system could comprise an attorney infact (AIF), authorized by the patient to decide on his behalf in case of a declaration of decision-making incompetence, and a legal representative (LR), assigned by law or appointed by a judge. Possibly, even more than one person can act as a legal representative (LR1, LR2), e.g., when the patient is underaged, when a judge appoints two persons as a guardian, when there are separate judicial measures for personal affairs versus financial affairs, and when a legal entity is appointed as representative, with possibly multiple persons performing the tasks of that entity.

Several more actors make up what can be called the *problem-solving support system*. We have already explained the patient advocate (PA), the topic of this paper. Since 2016, Dutch law also recognizes the statutory obligation for the care provider to have a complaint functionary (CF), whose position is less clear than that of the pa-

tient advocate, and who is usually employed by the hospital. Another actor could be a mediator (M), who is strictly neutral in conflicts between a patient and healthcare professionals. If such a mediator is associated with the Mediators' Federation of the Netherlands, the mediator has to follow a method of working with several legal aspects. For relatives of psychiatric patients, the function of a family advocate (FA) has been created. The General Data Protection Regulation, a European Union regulation, has also created the role of the data protection officer (DPO), dealing with matters of privacy.

The year 2019 saw the introduction of a disciplinary complaint functionary (DCF), who can inform and assist the patient who considers submitting a complaint before a disciplinary court. Next, there are two types of independent client supporters (ICS1, ICS2), one for municipal matters in the social domain and the other for matters relating to long-term care. A patient who plans to invoke the decision of a judge can appeal to the aid of a solicitor or a barrister (S/B).

More actors come into play when the patient intends *taking a conflict higher up*. For example, there is the medical superintendent (MS, the head of the ward (HOW), managing directors/governors (MD/G), an independent complaint committee (ICC), judges (J1, J2), disciplinary bodies of professional societies (DB), e.g., of the Dutch Association of Psychologists, arbitration boards (AB) and, finally, the health inspectorate (HI), whose task is to oversee compliance of healthcare law.

All these actors can be active in one and the same situation around one and the same patient, albeit this is not always the case. The aim of the diagram is to illustrate the large number of possible actors, the diversity of their roles (many of which are defined not only psychologically and socially, but also legally), and the complications that might arise in assessing their interrelationships.

The above enumeration is far from exhaustive. For example, no attention was paid to situations in which child and youth welfare

agencies or forensic authorities are involved, nor to the role of psychiatrists who provide medical expertise through their declarations in legal proceedings. Nonetheless, the diagram shows that, given the large number of roles and the heterogeneous pieces of legislation regulating them, we should not take it for granted that every actor's role is well coordinated with the other actors' roles on the regulatory level. Even if this were the case, the risk is real that, on the practical level, not all actors exactly know their own and one another's roles. Misunderstanding of roles and deviation from one's own role could get the system to stagger and to produce unwanted effects.

An example might be the situation in which a healthcare professional with limited knowledge of the law is not aware of the partial nature of the patient advocate's services (see the sixth cornerstone above); this healthcare professional might think that, in order to abide by the law, he has to stick to the patient advocate's conclusions, thereby possibly missing other essential considerations for decision making.

Although one of the aims of patient advocacy in psychiatry was to restore a perceived imbalance of power, a problem of the Dutch model might be that the introduction of the patient advocate has created a new sort of power imbalance, in that the legal know-how of the patient advocate supporting a psychiatric patient exceeds that of the average healthcare professional. Thus, a conflict arises with the idea of 'equality of arms', i.e., a legal principle with a view to fair procedures and poised decision making. A solution to this problem could be sought in instituting partial legal advocacy for healthcare professionals too. However, this might render the healthcare system even more complex.

*b) The quality of positive law*

As a result of positive law's being the basis for patient advocacy, flaws in positive law make themselves felt in patient advocacy. Problematic

developments in law also take place in international law, e.g. in relation to articles 12 and 14 of the *Convention on the Rights of Persons with Disabilities* (General Assembly of the United Nations, 2006). The present section will limit itself to Dutch law.

Two implications of developments in Dutch positive law for patient advocacy will be discussed. Firstly, we will reflect on those implications connected to developments regarding the design and number of regulations in general. Then two examples will be given illustrating effects that concrete pieces of legislation might have for patient advocates and others who might object to their provisions.

1. *The design and number of regulations.* In a civil law system, like the Dutch, the legislature's aspiration is traditionally to accommodate new legislation in a systematic, consistent, legal framework, preferably a code, emphasizing the main ethical and legal principles and highlighting the relationship among the various rules. Such an abstract framework would consist of a limited number of rules. It would leave room for the common sense of those who have to interpret and apply the rules, and it would enable them to devise a fair, concrete solution to the legal problem at hand, taking into account relevant aspects of the individual situation.

The legislature seems to have abandoned this aspiration. Legislation that has been enacted during the last ten to twenty years often has a different design. These laws seem intended for persons who can only carry out concrete instructions specified for them. Such laws attempt to regulate and formulate legal answers to any conceivable problem. Of course, the legislature cannot oversee all problems that might arise in practice, let alone foresee all possible future problems. Hence, every new problem requires a new regulation, giving yet another prescription to solve this problem.

This questionable tendency in recent Dutch legislation has several undesirable consequences. It results in a large number of regulations, containing nearly endless enumerations of concrete prescriptions and instructions. Not only is it hard for healthcare

professionals who are supposed to abide by these rules and keep track of them, the legislature itself, too, has difficulty in surveying its own output, which increases the chance that new legislation will contain duplications, inconsistencies, gaps and lack of clarity in view of previous legislation.

This leads to a certain degree of arbitrariness. Also, it can make healthcare professionals and others uncertain regarding what to do. They tend to adopt a passive attitude in relation to legal matters, expecting the law to provide concrete answers, and they are less prone to use their common sense and reason to arrive at solutions to legal and ethical problems. A passive attitude, in turn, engenders the need and the demand for more regulations, thus causing a vicious spiral in which regulations meant to solve problems are really creating new problems. Concretist regulations of poor design give rise to more concretist regulations of poor design.

Lastly, because of their aim to provide concrete instructions for action, many rules will focus on administrative provisions prescribing the observance of procedural steps, the use of standard forms, and the reporting of information and events (e.g., in the form of record keeping and incident notification). This focus may stimulate a bureaucratic mentality and obscure the rationale of the regulations.

Insofar as minor details indeed take up a disproportional amount of space in regulations, chances are that the legal questions and suggestions brought forward by patient advocates at the patient's request will have healthcare professionals occupy themselves with these details. Since time can only be spent once, this will distract attention from crucial substantial considerations, possibly endangering the quality of health care.

For the purpose of illustration, here are some statistics that indicate regulative activity in the Netherlands. The number of statutory articles in successive statutes dealing with compulsory psychiatric treatments has increased with every new act: the Lunatics Act comprised about 44 articles, the Special Admissions into Psy-

chiatric Hospitals Act about 80 articles, and the Mandatory Mental Health Care Act about 134 articles. The number has tripled in 26 years.

In forensic psychiatry, the number of legal positions on psychiatric patients is 26 at the moment of writing. One can imagine the problems this sheer number of regulations causes for those who have to implement them.

When making or modifying legislation, the legislature has to seek advice from the Council of State. During the last twenty years, the legislature has obtained 10,228 advisories from this Council, of which 889 pertained to health. This amounts to more than 40 concept-regulations each year on average or about one each week.

The legislature is not the only body producing regulations. Other organizations active in the field of psychiatry do so as well. Examples of these organizations are professional societies, the health inspectorate and organizations of hospitals. Their guidelines are collected by the legal section of the Dutch National Foundation, and they are put on this Foundation's intranet, because they contain additional norms that may be relevant to issues arising in mental health care. At present, more than 200 guidelines by such organizations can be found there.

It does not seem unreasonable to assume that the quality of regulation varies inversely as its quantity. In architecture, the phrase 'less is more' is well-known. For a legal context, I would like to express a variant, i.e., 'more is not always better'. If the assumption just mentioned is correct, an excessive amount of regulative activity leads to a low quality of regulations, which will hamper health-care professionals instead of helping them respect important legal and ethical principles in practice.

2. *Two examples of legislation with questionable content.* When the legislature enacts regulations with possible detrimental effects, patient advocacy based on positive law could itself contribute to the realisation of these effects. We will discuss two examples of Dutch

legislation that, to me, seem questionable: one pertaining to the right to file complaints and to request compensation for damages, the other pertaining to euthanasia.

First, by law, patients in the Netherlands have an unlimited right to file complaints, possibly before a complaint committee. A patient can submit the same complaint as often as she or he wants to. This is because the complaint regulations under consideration do not have a term during which the complaint functionary or the complaint committee may exclude and leave unconsidered any complaint similar to one already judged when there are no new facts. In addition, increasingly, the legislature links patients' right to file complaints to a right to request compensation for damages. These rights apply to psychiatric patients too. In the case of involuntary psychiatric care, the legislature has provided special complaint regulations.

The combination of a right to file unlimited number of complaints, coupled with a right to request compensation for damages, has its risks. Some patients may come to see complaining as an agreeable pastime comparable to gambling, especially when other possibilities to spend the day in a meaningful way (e.g. therapeutic programmes) are scarce. More seriously, these rights may shift the emphasis in the interaction between patient and healthcare professional from a collaborative discussion of good care to a legal combat about failings and money. Patients and professionals become parties in a conflict, bent on defeating the other party. It is easy to see that an adversarial legal approach could lead to an escalation of conflicts.

More adverse effects could occur. Being involved in complaint proceedings could also hamper the patient's psychological ability to reconcile herself or himself with involuntary care when it is necessary. This is all the more the case when the reasons underlying the committee's rejection of a patient's complaint are incomprehensible to the patient. A negative ruling might even result in an increase in the patient's anger and resistance to necessary treatment, and with

that, also an increase in the applying measures to compel the patient to receive this treatment.

Second, as is the case with other Western countries, Dutch health law has placed a rather one-sided emphasis on the principle of respect for individual autonomy. The most notable example of this in the Netherlands is perhaps the Dutch euthanasia act. Opinions on the moral permissibility of euthanasia vary widely, ranging from passionate support to profound opposition. If one has moral objections to this act, these objections might be stronger in relation to vulnerable patient groups, such as psychiatric patients. This concern is not without foundation, as the number of euthanasia cases performed on the basis of suffering that is primarily of psychiatric nature, has steadily increased according to the notification statistics in the annual reports of the Dutch euthanasia review committees.

The trend is to extend the possibilities of euthanasia without changing the statutory criteria. These processes of normalization and facilitation also concern euthanasia among psychiatric patients. Thus, the Royal Dutch Medical Association and the Dutch Association for Psychiatry have postulated a duty for physicians with conscientious objections to refer to a physician who is willing to provide euthanasia, in spite of the fact that they do not always use the term 'refer' in this regard. Moreover, the latter association also expects the conscientious objector to prepare decision-making regarding euthanasia for a psychiatric patient.

If these ideas are further incorporated into Dutch positive law, e.g. through case law, the patient advocate who objects to euthanasia on moral grounds might be compelled to play an instrumental role in implementing it. For instance, the moment might come when such a patient advocate may have to take the initiative to inform suicidal psychiatric patients about the possibility of euthanasia, if this advocate thinks the patient might be interested in that possibility.

To conclude, not only does the patient advocate act as an amplifier of the patient's voice, she or he can also act as an amplifier of ill-considered –or even immoral– elements in the law, by simply following positive law in combination with a patient's wishes, as the advocate's role prescribes him to do. This role has been constructed on the assumption that parties other than the patient advocate are in the position to criticize positive law when this is necessary, such as through democratic processes influencing the legislature. An assessment of whether this is a well-founded assumption is beyond the scope of this paper. At the end of the day, the patient advocate within the Dutch mental health system has no moral advocate for herself or himself, but legally must support whatever patients or governments ask for.

## Bibliographic notes

<sup>1</sup> In Dutch: «Wet bijzondere opnemingen in psychiatrische ziekenhuizen», abbreviated as «Wet Bopz» (*Stb. Netherlands*, 1992: 669). [https://doi.org/10.1007/978-90-313-8643-7\\_41](https://doi.org/10.1007/978-90-313-8643-7_41)

<sup>2</sup> Earlier, in 1985, the figure of the patient advocate was already mentioned in a governmental regulation called «Besluit eisen voor erkenning van ziekenhuizen» (*Stcr. Netherlands*; 1984; 234 & *Stcr. Netherlands*; 1985; 223).

<sup>3</sup> See articles 57-59 «Wet zorg en dwang psychogeriatrische en verstandelijk gehandicapte cliënten» (*Stb. Netherlands*; 2018; 36).

<sup>4</sup> Neither should there be legal barriers. This feature is discussed under the fourth cornerstone.

<sup>5</sup> See article 3 «Besluit patiëntvertrouwenspersoon Bopz». A patient advocate will not use this and other rights, if the patient does not want him to. See the eighth cornerstone.

<sup>6</sup> Of course, an important question is how «the evident necessity [...] to prevent serious harm» is defined. This is not the place to go further into this question.

<sup>7</sup> That is to say that these things do not matter for the availability of the patient advocate. Of course, they do matter when they are relevant in the legal analysis the patient advocate will give at the patient's request of a health care professional's behaviour or decision (cf. the fifth cornerstone).

<sup>8</sup> See the introduction of section I.

<sup>9</sup> A metaphor to illustrate this point could be a computer, which starts functioning differently as soon as new software has been installed on it.

<sup>10</sup> Cf. the role of a lawyer in a criminal proceeding, whose only task is to defend the suspect; obviously, putting forward incriminating evidence is important too, but it is the task of someone else, i.e., the public prosecutor.

<sup>11</sup> E.g., when the patient wants a pack of cigarettes, it is not up to the patient advocate to buy it in the store across the street. The reason for that is not because smoking is unhealthy, but because the patient advocate is not the patient's errand-boy. In this example, the patient advocate could only investigate whether the hospital has a responsibility to provide the patient with the opportunity to get cigarettes, and if so, help the patient call the hospital to account, if necessary. <https://doi.org/10.31353/cs0561>

<sup>12</sup> See the first cornerstone discussed above.

<sup>13</sup> See the introduction of section I.

<sup>14</sup> In Dutch this regulation is called «reglement Klachtencommissie Stichting PVP».

<sup>15</sup> Van Koeven H, Köhler H, editors. *Jaarverslag 2018: Voorbereiden op de Wvggz doen we samen*. Utrecht: Stichting PVP; 2019. Available from: <https://www.pvp.nl/Over-de-Stichting-PVP/Publicaties>. [https://doi.org/10.1007/978-90-313-8643-7\\_145](https://doi.org/10.1007/978-90-313-8643-7_145)

<sup>16</sup> The annual report does not specify this category, but an example of a limitation of freedom might be being put on a closed ward against one's will.

<sup>17</sup> In Dutch this arbitration board is called «Geschillencommissie Geestelijke Gezondheidszorg» (<https://www.degeschillencommissiezorg.nl/over-ons/zorgcommissies/geestelijke-gezondheidszorg/>).

<sup>18</sup> The abbreviations between brackets are used to refer to the actors at hand.

<sup>19</sup> In Dutch: «curator», «mentor» or «bewindvoerder».

<sup>20</sup> *Stb.* Netherlands, 2015; 407; *Stb.* Netherlands, 2015; 525.

<sup>21</sup> In Dutch: «Mediatorsfederatie Nederland» (Mfn) (<https://mediatorsfederatieneederland.nl/>).

<sup>22</sup> In Dutch: «familievertrouwenspersoon» («fvp»), transliterated as 'family confidentiality person' (see articles 12: 1-12: 4 «Wet verplichte geestelijke gezondheidszorg»; *Stb.* Netherlands, 2018; 37.

<sup>23</sup> Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC. <https://doi.org/10.5593/sgemsocial2019v/1.1/s02.022>

<sup>24</sup> *Stb.* Netherlands, 2018; 260; *Stb.* Netherlands, 2019; 111.

<sup>25</sup> In Dutch: «onafhankelijke cliëntondersteuner (oco) sociaal domein Wet maatschappelijke ondersteuning & Participatiewet».

<sup>26</sup> In Dutch: «onafhankelijke cliëntondersteuner (oco) Wet langdurige zorg».

<sup>27</sup> In Dutch: «geneesheer-directeur».

<sup>28</sup> In fact, at least five different possible judges might be resorted to, i.e., a special judge dealing with matters related to involuntary commitment («Bopz-rechter»), the regular civil court, a Justice of the Peace (in Dutch: «kantonrechter»), a special judge deciding in summary proceedings for urgent cases ( in Dutch: «voorzieningenrechter (bij kort geding)») and a disciplinary court (in Dutch: «tuchtrechter»).

<sup>29</sup> In Dutch: «verenigingstuchtcolleges».

<sup>30</sup> In Dutch: «College van Toezicht Nederlands Instituut van Psychologen». Available from: <https://www.psynip.nl/uw-beroep/tuchtrecht-en-klachten/tuchtcolleges/>.

<sup>31</sup> See footnote 18.

<sup>32</sup> E.g., the Child Welfare Council, a family guardian, youth care institutions.

<sup>33</sup> E.g., the Public Prosecutor, a criminal court, the director of a penitentiary institution, resettlement and rehabilitation bodies.

<sup>34</sup> See Welie SPK, Widdershoven TP. VPH en dwangpsychiatrie: hoe verder? Een aanzet voor een principieel debat. *Tijdschrift voor Gezondheidsrecht*. 2018; 42(1): 6-22. <https://doi.org/10.5553/tvgr/016508742018042001002>

<sup>35</sup> I have used the term 'legislative incontinence' in this respect; see Welie S, Ruissen A. Bijwerkingen van wilsbekwaamheidsbeoordeling. In: Hein I, Hondius A, editors. *Wilsbekwaamheid in de medische praktijk*. Utrecht: de Tijdstroom; 2018: 59-77.

<sup>36</sup> In Dutch: «Krankzinnigenwet».

<sup>37</sup> See footnote 2.

<sup>38</sup> In Dutch: «Wet verplichte geestelijke gezondheidszorg»; entry into force: January 1, 2020. See footnote 23.

<sup>39</sup> Stichting PVP. Schema forensische verblijfstitels (Internal publication). Utrecht; 2018.

<sup>40</sup> In Dutch: «Raad van State».

<sup>41</sup> Source: website Council of State, consulted on 20 August 2019. Available from: <https://www.raadvanstate.nl/adviezen/>

<sup>42</sup> Usually Ludwig Mies van der Rohe is mentioned as the architect having adopted this motto. Source: wikipedia, Cited 20 August 2019. Available from: [https://en.wikipedia.org/wiki/Ludwig\\_Mies\\_van\\_der\\_Rohe](https://en.wikipedia.org/wiki/Ludwig_Mies_van_der_Rohe). <https://doi.org/10.1093/anb/9780198606697.article.1700886>

<sup>43</sup> See article 20 «Wet kwaliteit, klachten en geschillen zorg» (*Stb.* Netherlands; 2015; 407 & *Stb.* Netherlands; 2015; 525).

<sup>44</sup> See articles 41-41b «Wet bijzondere opnemingen in psychiatrische ziekenhuizen» and articles 10: 1-10: 13 «Wet verplichte geestelijke gezondheidszorg». [https://doi.org/10.1007/978-90-313-6305-6\\_13](https://doi.org/10.1007/978-90-313-6305-6_13)

<sup>45</sup> *Stb.* Netherlands; 2001; 194 & *Stb.* Netherlands; 2002; 165.

<sup>46</sup> In 2012 (the first year on which the annual report explicitly contains 'psychiatric conditions' as a separate categorie) there were 14 psychiatric cases on a total of 4188 notifications (i.e. 0,33%) and 42 dementia cases (i.e. 1,00%). In 2018 –six years later– these figures were 67 psychiatric cases on a total of 6 126 notifications (i.e. 1,09%) and 146 dementia cases (i.e. 2,38%). Source: annual reports euthanasia review committees. Available from: <https://www.euthanasiecommissie.nl/de-toetsingscommissies/jaarverslagen>.

<sup>47</sup> Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst. Standpunt Federatiebestuur KNMG inzake euthanasie; 2003: 8.

<sup>48</sup> Nederlandse Vereniging voor Psychiatrie. Levensbeëindiging op verzoek bij patiënten met een psychische stoornis; 2018; 48.

<sup>49</sup> Nederlandse Vereniging voor Psychiatrie, Levensbeëindiging op verzoek bij patiënten met een psychische stoornis; 2018; 145.