

The Legal Position of Vulnerable People in the Future: Improving or Going Backwards?

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Abstract

Two vulnerable groups in our society are children with psychiatric problems and people with intellectual disabilities. The demand for care is growing every year in both groups. The current (Dutch) legal status of people with intellectual disabilities and children with psychiatric problems is one in which too much attention is devoted to the right to self-determination. An important question is whether this central feature is enough to support clients in both groups in such a way that they can develop their abilities. The Dutch government is currently preparing new legislation to replace the Psychiatric Hospitals Act. We recommend that this legislation should also take account of the right to development and the right to good care in order to deal with the dilemmas that will arise in the near future.

Keywords

children with psychiatric problems; people with intellectual disabilities; right to self-determination; right to good care; right to development; Dutch Psychiatric Hospitals Act; current and future legal status

1. Introduction

This article makes a link between care for the elderly on the one hand, and care for people with intellectual disabilities and children with psychiatric problems on the other. People with intellectual disabilities are now living longer, and more young people are suffering psychiatric problems. Both these groups will ultimately become older, and so the conclusions drawn in this article will also be of relevance to elderly people in general.

Patients' rights have attracted particular interest in the Netherlands since the 1990s, with a great deal of legislation coming into force since then. A central feature of the various Acts is that they all focus on the right to self-determination. This right, which is seen as one of the basic principles in health law, presupposes freedom, whereby individuals have the right to decide how to shape their own lives.¹ Legislation to date has been based on a very narrow interpretation of

¹⁾ J. Legemaate, "Het zelfbeschikkingsrecht: een oud debat in nieuw licht", *Tijdschrift voor Gezondheidsrecht* 28 (2004), pp. 18-20.

self-determination. In the 1990s legislation seemed to operate on the basis of a defence or, in other words, the right to structure your life in the way of your choosing and without interference by others.^{2,3}

The right to self-determination is not limited to people with specific qualities. In Leenen's opinion,⁴ the right to self-determination is also available to people unable to enjoy it. The central idea is that everything possible should be done to enable each individual to realize this right, taking into account all opportunities and limitations. This basic principle also, therefore, applies to people with intellectual disabilities and to young people with psychiatric problems. This is explicitly stated in the preamble of the United Nations Convention on the Rights of Persons with Disabilities.⁵

In recent years various dissenting voices about the actual meaning of self-determination in health law have been heard, with some health law specialists believing that this emphasis on self-determination threatens the equilibrium in health law.^{6,7,8} These discussions are a particularly sensitive issue for those groups on which this article focuses. Will these people get the right care if the primary focus is on self-determination? Adopting a too individualistic view to self-determination can potentially represent a threat to vulnerable individuals, such as those with intellectual disabilities and young people with psychiatric problems, as placing too much emphasis on self-determination can result in these individuals not receiving the appropriate care.⁹

The current legal framework for restrictive measures is very likely to be replaced by new legislation in the near future. The way in which this legislation deals with self-determination is very important. Will it continue adhering to a narrow interpretation of self-determination? Or will scope be created for a wider interpretation that also allows account to be taken of two very relevant principles for people with intellectual disabilities and children with psychiatric problems; in other words, the right to receive good care and the right to development. Many of these people have a long life ahead of them, and can each, in their individual way,

² H.J.J. Leenen, J.K.M. Gevers and J. Legemaate, *Handboek gezondheidsrecht. Deel I: Rechten van mensen in de gezondheidszorg*, (The Hague: Boom Juridische uitgevers, 2011) 38.

³ A. Hendriks, B.J.M. Frederiks and M. Verkerk, "Autonomie: dankzij of ondanks goede zorg?", *Tijdschrift voor Gezondheidsrecht* 32 (2008) 2.

⁴ *Supra* note 2.

⁵ United Nations Convention on the Rights of Persons with Disabilities, Preamble (under n): Recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.

⁶ A.C. Hendriks, *In beginsel. De gezondheidsrechtelijke beginselen uitgediept*, (Leiden: Stichting NJCM-Boekerij, 2006), p. 11.

⁷ V.E.T. Dörenberg, *Kind en stoornis. Een systematisch onderzoek naar de rechtspositie van minderjarigen in de kinder- en jeugdpsychiatrie* (diss.), (The Hague: Boom Juridische Uitgevers, 2010), pp. 372-373.

⁸ B.J.M. Frederiks, "The rights of people with an intellectual disability in the Netherlands: From restriction to development", *European Journal of Health Law* 14 (2007) 149-163.

⁹ *Supra* note 3, p. 3.

develop as a person. But that demands appropriate care. Another relevant question concerns the consequences that the focus on self-determination has for the future of the two groups, assuming that both ultimately become elderly. Can they grow old with confidence?

Based on the above issues and the various questions posed, the central question in this article is whether the right to self-determination is still the best principle in health law, particularly in respect of the care provided to people with intellectual disabilities and children with psychiatric problems. Against the background of changes in client populations, but also in beliefs about care and support, we discuss whether more attention needs to focus on other principles in health law and what the consequences of this will be for the right to self-determination. At the end of this article we discuss the consequences that our findings have for the target group of elderly people.

2. Two Groups of Vulnerable People

Traditionally, it is a government's duty to protect, respect and fulfil the rights of its citizens and those under its jurisdiction. These include certain groups of people who are particularly vulnerable in view of their specific problems, risks and needs. One of these special groups is children. In view of their dependence on adults, children are at particular risk and require special attention to overcome their vulnerability to physical and psychological trauma and to deal with the developmental needs to be met if they are to be assured of normal growth and development. This is why children can be taken into care if their parents put them at risk or are unable to fulfil the children's needs.

Psychiatric problems make children even more vulnerable and thus add to their problems, risks and needs. Most Dutch epidemiological studies show a diagnosed mental disorder in about 20 per cent of children under the age of 18.¹⁰ Some studies even report prevalence rates above 30 per cent,¹¹ but this does not mean that all these children require mental healthcare. That depends on the severity of the problems. *GGZ Nederland*, a Dutch mental healthcare organization, estimates that about 5 per cent of Dutch children have psychological or psychiatric problems of such severity that they cannot function properly in daily life.¹²

¹⁰ See S. Sytma et al., *Verkenningen in de Kinder- en Jeugdpsychiatrie*, (Utrecht: Trimbos Institute, 2006), p. 12, referring to the HBSC study in 2002 (T. ter Bogt, S. van Dorsselaer and W. Vollebergh, *Psychische gezondheid, risicogedrag en welbevinden van Nederlandse scholieren*, (Utrecht: Trimbos Institute, 2003) and the study of Verhulst et al. in 1997 (F.C. Verhulst et al., "The prevalence of DSM-III-R diagnoses in a national sample of Dutch adolescents", *Archives of General Psychiatry* 54 (1997), pp. 329-336).

¹¹ H.G. Bosweger et al., *Jeugd-ggz breed beschikbaar. Ambities voor de jaren 2006-2008*, (Amersfoort: GGZ Nederland, 2007), p. 15, note 2. The note refers to F.C. Verhulst, "Kinder en Jeugdpsychiatrie", in: A. de Jong et al., *Handboek Psychiatrische Epidemiologie*, (Maarssen: Elsevier/De Tijdstroom, 1999). It is noted that prevalence rates vary, mainly because of differences in definitions and research methods.

¹² *Ibid.*, p. 15.

According to the Trimbos Institute, another Dutch mental healthcare organization, at least 7 per cent have such serious problems that they require professional care.¹³ Although the number of children actually using mental healthcare services is considerably lower at about 2-3 per cent,^{14, 15} numbers have clearly grown over the years. Between 2007 and 2009, the number of clients in the child and youth mental health sector increased by 18 per cent.¹⁶ As a result, 140,569 children under the age of 18 received treatment in 2009 for mental disorders.¹⁷ The usual reason for referring a child to a psychiatrist is behavioural problems.¹⁸

In most cases, ambulatory or outpatient treatment is sufficient to help a child with psychiatric problems, but sometimes the problems are so severe that the child has to be admitted to a psychiatric hospital. In 2009, 96 per cent of clients in the child and youth mental health sector received ambulatory treatment.¹⁹ This means that child admissions to a psychiatric hospital are relatively rare. However, the heightened legislative focus and media attention on the use of seclusion and restraint in psychiatric facilities, particularly among minors, have made admission an important topic.

The vast majority of admissions in the child and youth mental health sector are considered voluntary. Voluntary admissions occur in much the same way as admissions to a general hospital. Although Dutch law requires the referral to be made by childcare services, most referrals are in practice made by the family's general practitioner.²⁰ For the admission to be considered voluntary, the child and/or its parents (or legal guardian) have to give informed consent. Children over the age of 12 have the legal right to refuse treatment in a psychiatric hospital. In that case, the child may have to be admitted as an involuntary patient.²¹ The

¹³ *Supra* note 10.

¹⁴ *Supra* note 12.

¹⁵ *Supra* note 7, p. 7, note 21.

¹⁶ GGZ Nederland, *Zorg op waarde geschat. Update. Sectorrapport ggz 2010*, (Amersfoort: GGZ Nederland, 2010), p. 19. This report also reveals that, between 2005 and 2009, the largest increase in mental health clients was in the child and youth mental health sector, where the number of clients increased by 60-75 per cent (p. 27).

¹⁷ *Ibid.*, p. 22.

¹⁸ *Ibid.*, p. 29.

¹⁹ *Ibid.*, p. 40. Between 2007 and 2009, ambulatory treatment in the child and youth mental health sector increased by 23 per cent.

²⁰ *Ibid.*, p. 21.

²¹ Article 5 of the European Convention on Human Rights protects everyone's right to liberty and states that a deprivation of liberty has to be in accordance with a procedure prescribed by law. Whether admission to a psychiatric hospital amounts to deprivation of liberty depends on a whole range of criteria such as type, duration, effects and manner of implementation of the measure in question. In the case of *Nielsen v. Denmark* (Judgement of 28 November 1988, *Series A* (1988) No. 144), the Court held that the hospitalization of a 12-year-old boy in a psychiatric ward by virtue of a decision by the mother as sole holder of parental rights did not amount to deprivation of liberty but was a responsible exercise by the mother of her custodial rights as protected by Article 8 of the Convention. Under Dutch law, a 12-year-old child could not have been admitted involuntarily solely by virtue of a decision of (one of) its parents. A court order would have been necessary.

rules for formal admissions are set out in the Psychiatric Hospitals Act. In order for an individual to be admitted by court order, each of the following must apply: the individual has a mental disorder (being mental illness, an intellectual disability or dementia); the individual represents a danger to himself, others or society; the danger is caused by the mental disorder; the individual is over the age of 12 and unwilling to be admitted voluntarily; and there is no less restrictive form of care or treatment available to meet his needs.²² If an individual appears to be suffering from a mental disorder and is in clear and imminent danger of harming himself or others, the mayor can also order emergency admission.²³ The requirements for formal admissions are hardly ever met in the case of children. In 2007, there were 330 formal admissions to child and youth mental health facilities, while the number in 2008 totalled 276.²⁴ Comparing these numbers to the total number of admissions — roughly four to five thousand children a year receive some sort of psychiatric hospital care²⁵ — and assuming most children will not readily agree to be taken out of their homes and placed in a psychiatric hospital, this can only mean one thing. Care providers devote a lot of time and energy to seeking to persuade children and their parents to consent to admission.²⁶ If they fail, however, treatment cannot take place and the child will then remain at risk. This raises the question of whether the legal framework for treating children with psychiatric problems is suited to protecting their best interests.

The second group needing extra attention and protection is people with intellectual disabilities. Recent figures show there to be around 115,000 people in the Netherlands with an intellectual disability.^{27, 28} The number of people with a serious intellectual disability (IQ <50), is around 60,000, while the number with a mild intellectual disability (IQ of between 50 and 70) is around 55,000. Although the current figures have remained reasonably stable, the target group is becoming increasingly older because of the general rise in life expectancy rates and the fact that this includes people with a serious or mild intellectual disability.²⁹ In addition, the need for care within the target group is increasing by around 9 per cent

²² See Article 2 of the Dutch Psychiatric Hospitals Act.

²³ See Article 20 of the Dutch Psychiatric Hospitals Act.

²⁴ *Supra* note 7, pp. 12 and 425.

²⁵ *Supra* note 16; the estimated number of children who receive psychiatric hospital care is deduced from pp. 32 and 40.

²⁶ Indeed, the first and second evaluation of the Dutch Psychiatric Hospitals Act showed that care providers in the child and youth mental health sector go to great lengths to get informed consent (C. de Groot and M. Donker, *Evaluatie Wet Bopz. Deelonderzoek 10-6: De Wet Bopz in de kinder- en jeugdpsychiatrie*, (The Hague: ZonMw, 2002), pp. 7 and 38).

²⁷ M. Ras, I. Woittiez, H. van Kempen and K. Sadiraj, *Steeds meer verstandelijk gehandicapten? Ontwikkelingen in vraag en gebruik van zorg voor verstandelijk gehandicapten*, (The Hague: Social and Cultural Planning Office, (4) 2010).

²⁸ Estimates vary from 112,000 to 120,000.

²⁹ M. Maaskant and J. Hoekman, *Veroudering bij mensen met verstandelijke beperkingen. Vademecum Zorg voor Verstandelijk Gehandicapten*, (2007).

a year, in part because of the improved recognition of slight intellectual disabilities and society's growing demands. Young people (up to the age of 22) account for almost half the total growth in demand for care for people with intellectual disabilities because of the increasing behavioural, addiction and adhesion problems experienced in this age group.

People with intellectual disabilities are a vulnerable group. Many clients, most of them for a long time and some for the rest of their lives, are dependent on a range of care providers. Around half the clients with an intellectual disability require some form of support in daily life, varying from 24-hour care to a few hours of help at home. Various studies have found that many of these clients experience some restrictions to their freedom on a daily basis.³⁰ Considerable efforts have been made over the past few years to achieve a change of culture in the sector, and care providers are now increasingly aware of the negative consequences of using restraints.³¹ Many staff are looking for alternatives to invasive measures such as tethering bands and seclusion. However, there are no recent figures showing the extent to which measures restraining the freedom of people with an intellectual disability are used or whether their use is being reduced.

In the Netherlands, the Psychiatric Hospitals Act provides the legal framework under which the freedom of this target group may be restricted. It allows care providers to apply freedom restrictions, but only if certain conditions are met. The central feature of this Act is the right to self-determination, and this means that care providers are only allowed to intervene in a client's life in certain circumstances. By 2002 it was clear that this Act did not provide the correct legal protection for people with an intellectual disability.³² Many clients who face restrictions on their freedom do not fall within the scope of the Act, but are nevertheless exposed to such restrictions. Meanwhile clients who are covered by the Act do not always enjoy all the 'benefits' that it provides. The Psychiatric Hospitals Act is complex and focuses too much on psychiatry, with little opportunity to involve courts or the Healthcare Inspectorate. Very few clients use the right of complaint available to them under the Act, while the role assigned to confidential counselors is not well suited to dealing with people with intellectual disabilities, and many forms of freedom restriction are not recognized as such and are thus applied outside the provisions of the Act or do not meet the statutory requirements. Opposition by a client is certainly not always taken seriously. A more important issue, however, is whether the characteristics of the Act allow care providers to

³⁰ B.J.M. Frederiks, *De rechtspositie van mensen met een verstandelijke handicap. Van beperking naar ontplooiing* (diss.), (The Hague: Sdu Uitgevers BV, 2004).

³¹ Inspectie voor de Gezondheidszorg, *Cultuuromslag terugdringen vrijheidsbeperking bij kwetsbare groepen in langdurige zorg volop gaande. Duidelijke ambities voor 2011 nodig*, (The Hague: 2010).

³² L.A.P. Arends, K. Blankman and B.J.M. Frederiks, *Evaluatie Wet Bopz, Deelonderzoek 10-3: Interne rechtspositie in de psychogeriatric en de verstandelijk gehandicaptensector*, (The Hague: ZonMw, 2002).

support clients in a way that enables them to develop their abilities, even if this means that restraint is necessary.

The issue of restraints in the care for people with an intellectual disability was widely discussed in the Dutch media in January 2011. This followed a television documentary that featured Brandon, an 18-year-old boy with behavioural problems, who was mechanically restrained on a daily basis and had been held in a room without windows for 24 hours a day over a period of three years. This case is not unique, as a recent Health Care Inspectorate report documented 28 clients who had experienced long-term separation and/or fixation. The Inspectorate found the quality and safety of the care provided to people with intellectual disabilities to be inadequate. This shows that we still have a long way to go in the Netherlands in terms of the legal position of people with an intellectual disability.³³

3. Common Principles

3.1. *Self-determination (and Protection)*

The right to self-determination is seen as one of the basic principles of health law.³⁴ It primarily means that an individual has the right to decide for himself what to do with his life, without interference by others.³⁵ The right to self-determination is not as such defined in law, but some elements can be derived from various constitutional rights. Article 10 of the Dutch Constitution, for example, imposes a duty on the government to protect everyone's right to personal integrity. Article 11, concerning the inviolability of the human body, is a subspecies of the general right to personal integrity and protects against violations such as forced medical experiments, corporal punishment, torture and mutilation. Article 15 also protects the right to liberty. Similar provisions to protect these rights, and thus the right to self-determination, are found in European Conventions and other international treaties relating to human rights.

Although every individual has the right to self-determination, some people may not be able to exercise this right. Children, for example, are not able to exercise any rights at birth. Parents therefore bear the primary responsibility for their children and for exercising rights in the children's best interests. As children get older, their abilities to speak, think and reason will develop and they will become increasingly capable of making decisions for themselves. This is no different in the

³³ B.J.M. Frederiks, "Juridische houdbaarheid van vrijheidsbeperking rammelt. Brandon is meer dan een gevaar", *Medisch Contact* 66 (2011), pp. 548-550; Inspectie voor de Gezondheidszorg, *Kwaliteit van zorg bij langdurige vrijheidsbeperking van mensen met een verstandelijke beperking: vooral de dialoog ontbreekt*, (The Hague: 2011).

³⁴ *Supra* note 2, p. 37.

³⁵ *Supra* note 6, p. 5.

case of children with psychiatric problems, except for the fact that normal development is affected by mental disorders. In Dutch law, all children under the age of 12 are considered incapable of giving informed consent to medical treatment.³⁶ Children over the age of 12 are, in principle, considered capable of giving consent. The same can generally be said for people with intellectual disabilities. Although severe intellectual disabilities often make individuals incapable of making decisions for themselves, the mere fact that someone is intellectually disabled does not automatically make him incapable. A physician or care provider should determine whether a client is capable of giving informed consent for a specific decision and, in any case, should take account of the client's wishes and preferences. This also applies to legal representatives who have to make decisions for clients if the latter are considered incapable of doing so for themselves in a specific situation.

Individuals' right to self-determination can be restricted in order to protect the rights of others, to protect them from harm or to protect society as a whole.³⁷ In this way we recognize the right to protection, which includes accepting responsibility for people unable to defend their own interests (such as children and people with intellectual disabilities) and who need care and support.³⁸ Restricting individuals' right to self-determination in order to protect them from themselves has been widely criticized. However in people who are vulnerable, such as children, people with intellectual disabilities and psychiatric patients, this specific ground for restriction may be considered justified.³⁹ Indeed, the Psychiatric Hospitals Act allows for clients to be admitted if this is in their best interests. Formal admission is only, however, possible if the mental disorder is so severe that it affects a person's thinking, perceptions, emotions or judgment, and seriously impairs the person's mental function to such an extent that he requires care.⁴⁰

As stated above, the right to self-determination is primarily seen as a right to make decisions without interference by others; in other words, a right to be left alone. In vulnerable people, however, this negative interpretation of self-determination can easily lead to problems. Leaving these people alone may deprive them of the care they need. That is why clients considered incapable of making decisions for themselves should ideally have a legal representative. Even then, however, the legal grounds for treating clients against their will are very strict. The Psychiatric Hospitals Act specifically emphasizes the right to self-determination by setting strict rules for involuntary admissions and treatment. In the event of an

³⁶ See Article 465, Book 7, of the Dutch Civil Code.

³⁷ *Supra* note 2, p. 40.

³⁸ *Ibid.*

³⁹ H. van de Klippe, *Dwangtoepassing na onvrijwillige psychiatrische opname. Een juridische beschouwing*, (Nijmegen: Ars Aequi Libri, 1997), p. 205.

⁴⁰ W. Dijkers, "Artikel 2", in: W.J.A.M. Dijkers and T.P.J.C. Widdershoven (eds.), *De wet BOPZ: artikelgewijs commentaar*, (The Hague: Koninklijke Vermande (loose-leaf, with supplements)) note 2.4, pp. 38-39.

involuntary admission, psychiatric patients/clients can only be treated against their will if their mental disorder means they represent a danger to themselves or others or, if not treated, they would have to stay in the hospital for an unreasonable length of time.⁴¹ In emergency situations not foreseen in the treatment plan, clients admitted involuntarily can also be restrained or secluded for up to seven days.⁴² Here too, however, the mental disorder has to be such that there is a danger to the client or others. As these conditions are hardly ever met in the case of children with psychiatric problems and people with intellectual disabilities, and they therefore risk being deprived of the care they need, the prevailing view on self-determination has come under attack.^{43, 44, 45}

At the same time, however, it is important to avoid unjustified paternalism; in other words, failing to take the wishes of the client seriously enough. There is a danger of people with intellectual disabilities too quickly being regarded as lacking the capacity to express their will. There are therefore various additional requirements for the duty of care that have to be met in respect of this group, and also in cases involving children.⁴⁶ Measures that restrict freedom, child-protection measures and requests to appoint a guardian or mentor are only regarded as legitimate if the client in question is unable to understand the consequences of his actions, if these actions are damaging to the client and if the measure complies with the subsidiarity, proportionality and effectiveness criteria, is carefully executed (including, for example, a note in the care plan, an assessment and the involvement of various disciplines) and contributes to the personal development of the client.⁴⁷ Looking again at the recent case of Brandon, we can see that the measure imposed — being tethered to the wall — did not meet these criteria. Admittedly Brandon was protected against the damage that could be caused by his own actions, but no weight appears to have been (or allowed to have been) attached to the other criteria. This case shows that the right to protection can also be interpreted too narrowly, and that this has certain consequences for the client's right to self-determination.

3.2. *Good Care*

The previous section considers the questions of self-determination and protection. Both elements are crucial for the personal development of clients with an

⁴¹ See Article 38(5) and 38c of the Psychiatric Hospitals Act.

⁴² See Article 39 of the Psychiatric Hospitals Act.

⁴³ G.A.M. Widdershoven, R.L.P. Berghmans and A.C. Molewijk, "Autonomie in de psychiatrie", *Tijdschrift voor de Psychiatrie* 42 (2000), pp. 389-390.

⁴⁴ *Supra* note 30, pp. 91-93.

⁴⁵ *Supra* note 7, pp. 99-102.

⁴⁶ These requirements for the duty of care apply both in respect of protective measures applied and limitations on self-determination.

⁴⁷ *Supra* note 30, pp. 96-97.

intellectual disability and for children. The two principles are closely related and can essentially be seen as two sides of the same coin. Together they combine to constitute good care. Good care implies an active duty of protection, focusing on encouraging clients' opportunities for development, irrespective of whether they are an adult or a child, and irrespective of whether they are capable or incapable of expressing their will.⁴⁸ The conditions applying in this respect are discussed in the previous section. Health law literature does not always regard good care as a separate principle, but often more as a modality of the right to healthcare or as part of the principle of protection.⁴⁹ Our view, however, differs.

The right to healthcare is laid down in Article 22 (1) of the Dutch Constitution and is a social human right. Although good care is based on this right, in many ways it shows the characteristics of an individual right and so may be compared to the right to self-determination. Good care is an accentuation of the right to healthcare and consists of three elements: quality, geographical accessibility and financial accessibility. The emphasis in good care is more on the provision of good-quality care, and less on the elements of availability and accessibility. In this context the right to good care may be described as 'care which is centred on the individual and which contributes to the development of the client'.⁵⁰

Care providers need to possess certain qualities to be able to offer such client-centred care. These qualities are referred to in the Dutch Civil Code as the 'professional standards applicable to providers of care'.⁵¹ Although the legislator provides only a general explanation of this term, the right to good care means the role of a care provider must be an active role. The provider must be able to empathize with the client and the client's situation in order to be able to contribute to the client's development. From this perspective, care can be seen as offering support to clients. In the modern interpretation, care is in many ways similar to support, with the emphasis no longer being on what the client is unable to do, but instead on empowering the client. Care providers' responsibilities are also, therefore, deemed to include being understanding and committed to helping clients to go forward. These are just some of the characteristics of good care.⁵²

In summary, providing good care means ensuring that the actions of a care provider are geared towards stimulating the abilities of a patient/client, despite any disabilities or psychiatric problems there may be. Instead of focusing on non-intervention, a focus on support where possible and necessary is preferable. As this

⁴⁸⁾ *Supra* note 3, p. 8.

⁴⁹⁾ *Supra* note 2, p. 42.

⁵⁰⁾ *Supra* note 30, pp. 101-106.

⁵¹⁾ Article 453, Book 7, Dutch Civil Code.

⁵²⁾ G. Widdershoven, R.L.P. Berghmans and S.P.K. Welie, "Zelfbeschikking of goede zorg? Ethische kanttekeningen bij juridisering in de hulpverlening", in: A.H. Schene et al., *Jaarboek voor psychiatrie en psychotherapie*, (Houten/Diegem: Bohn Stafleu van Loghum, 2003), pp. 325-338.

approach, however, may verge in the direction of paternalism, it is essential for care providers to be transparent in their actions and accountable to third parties.

3.3. *Development*

During the 20th century society came to realize that children, and also people with intellectual disabilities, are more than simply objects in need of protection. They are individuals and, therefore, subjects with their own rights and responsibilities, appropriate to their age and stage of development. This new view on the legal position of children was the basis for the Convention on the Rights of the Child, which sets the focus firmly on the right to development. Under the Convention, states must respect the rights and responsibilities of parents to provide guidance for the child appropriate to his evolving capacities. They are also obliged to ensure the child's development and to provide him with adequate care if his parents fail to do so.⁵³ This means that children rely primarily on their parents for invoking the right to development, but also on the government.⁵⁴ In Dutch Law, the main area in which the right to development is reflected is in family law and the regulations governing child and youth care. The 'best interests of the child' are almost always defined in terms of development.

Although the right to development is most frequently referred to in the context of children's rights and family law, it has also gained focus and attention in discussions on the legal status of people with intellectual disabilities.⁵⁵ The prevailing view is that these people should have equal opportunities and therefore be supported so that they are able to function as much as possible like any other group of people in society.⁵⁶ In other words, people with intellectual disabilities have a right to develop their abilities to the extent possible. Indeed, the Convention on the Rights of the Child states that disabled children have the right to special care to help them enjoy a full and decent life in dignity and achieve the greatest degree of self-reliance and social integration possible.⁵⁷ The same should apply in respect of disabled adults because reaching adulthood is by no means an indication that a client no longer needs some kind of support.⁵⁸ This principle also applies in respect of people with very serious intellectual disabilities who are nevertheless able to develop to some degree.

⁵³ Articles 3, 5 and 6 of the Convention.

⁵⁴ See M. de Langen, *Recht voor jeugdigen. Een onderzoek naar rechten en rechtsbeginselen in het jeugdrecht*, (Alphen aan den Rijn: Samsom Uitgeverij, 1973), p. 24.

⁵⁵ The right to development is explicitly mentioned in the Bill on the Principles of Long-Term Care [*Beginselenwet zorginstellingen*], which is intended for clients in the long-term care, including those with an intellectual disability.

⁵⁶ B.J.M. Frederiks, R.H. Van Hooren and X. Moonen, "Nieuwe kansen voor het burgerschapsparadigma: een pedagogisch, ethisch en juridische beschouwing", *Nederlands Tijdschrift voor de Zorg aan Mensen met Verstandelijke Beperkingen* (2009), pp. 3-30.

⁵⁷ Article 23 of the Convention.

⁵⁸ *Supra* note 8, p. 156.

There is a close relationship between the right to development and other principles of law. In general, the ultimate goal of human development is to maximize people's self-determination and personal responsibility. In a sense, therefore, self-determination is conditional to development. The fact that the development of vulnerable people is often impaired by a disorder serves to emphasize the need for support. It is only through support that these people can achieve a higher level of self-determination, as also stated in the United Nations Convention on the Rights of Persons with Disabilities. In the case, however, of children with psychiatric problems, simply providing support is not enough. They also need guidance and, of course, psychiatric treatment. This demands special care.⁵⁹ Dutch mental health law, however, focuses on treatment and on removing the danger that a client represents to himself or others. And this is not enough for the vulnerable people to whom we are referring.

4. Self-determination Revisited

When treating children with psychiatric problems, as well as caring for people with intellectual disabilities, there is an innate tension between respecting clients' right to self-determination and protecting them from harm. Care providers need to find a balance between these two principles, keeping in mind that clients also have a right to good care and a right to development. This demands a different perspective. By focusing (too much) on self-determination or protection, care providers do not provide children or people who have an intellectual disability with the care they need. A primary objective in providing care and support in both groups is to offer clients a perspective for the future. Although the right to self-determination may need to be restricted, that does not have to mean allowing clients or children to cease developing. A number of critical remarks can be made in this context with regard to the case of Brandon. Although the State Secretary and the Healthcare Inspectorate concluded that the legal criteria of the Psychiatric Hospitals Act had been met, Brandon deserved much better. The mechanical restraint had started three years earlier to remove the danger that Brandon represented to himself and/or others. In January 2011, however, it was unclear as to whether the danger still existed. What about Brandon's perspective? The Psychiatric Hospitals Act also contains three additional legal criteria for care providers to determine whether restraints are necessary in a specific individual case. Is the restraint in proportion to the intended goal? Can the restraint be replaced by a reasonable, less intrusive alternative? Is the restraint effective (i.e. does it contribute to achieving the intended goal?). According to the criteria, restraints of freedom must serve some *purpose*. The aim cannot solely be to remove the danger by

⁵⁹ *Supra* note 7, pp. 126 and 130.

providing safety for the client and society. However dangerous clients may be, if the care provided to them is to be good, it must include their right to support and a future. In our view, this case confirms the fact that care providers, but also the State Secretary and the Healthcare Inspectorate, apply a very narrow interpretation of the right to self-determination and protection. Respecting the rights of vulnerable clients demands more: as well as the right to self-determination, they also have a right to good care and development. An important question, therefore, is whether new legislation will create greater scope for these principles.

5. Replacing the Dutch Psychiatric Hospitals Act

5.1. *Background*

It is fair to say that the Dutch Psychiatric Hospitals Act has been subject to regular criticism, with one of the main points of this criticism being the broad scope of the Act. Not only does it set the rules for involuntary admissions and treatment of psychiatric patients, but it also applies to people with intellectual disabilities and those with dementia. These people, too, can be admitted by court order. The Act also sets out specific procedures for allowing such people to be admitted by a committee [*Bopz-indicatiecommissie*] if they are unable either to give or withhold consent for admission.⁶⁰ No judges sit on these committees. The rules for treatment are the same for all involuntary patients; in 2008, however, a distinction was made, when the grounds for involuntary treatment of psychiatric patients were extended.⁶¹ Nevertheless, the Act focuses mainly on psychiatry — adult psychiatry, to be more precise — and many of the rules are therefore not really designed for treating people with intellectual disabilities or dementia. Indeed, it is even incorrect to speak in terms of treatment. The first and second evaluations of the Act confirmed that the legislation was not suitable for people with intellectual disabilities or dementia as the legal status of these individuals was not well protected. In 2005, therefore, the Dutch government decided to devise a separate set of rules for these people, with a focus on and attention for all-round care rather than admissions.⁶²

Meanwhile, however, the legal position of psychiatric patients has also come under discussion. Firstly, the Psychiatric Hospitals Act is very complex legislation, providing for various different types of court orders, each with its own set of rules. The court order referred to in section 2 of this article is the one most commonly issued. Another concern is the fact that the Act emphasizes the right to

⁶⁰ See Article 60 of the Psychiatric Hospitals Act.

⁶¹ Act of 25 February 2008, *Bulletin of Acts and Decrees* 2008, 80; Articles 38a-38c.

⁶² See *Parliamentary Papers II* 2004/05, 28 950, No. 5.

self-determination and focuses on (intramural) admissions rather than on treatment. Courts are only involved in the admissions procedure. Over the years, however, the field of psychiatry has focused more and more on treating patients outside hospital walls. This led to a change in the law in 2004, when provisions for conditional ambulatory treatment were introduced into the Psychiatric Hospitals Act.⁶³ Even so, the Act is no longer considered 'future-proof', as the third evaluating committee pointed out.⁶⁴ In 2008, the Dutch government therefore decided to replace it by new legislation.⁶⁵

Finally, in 2009 and 2010, two legal frameworks designed to replace the Psychiatric Hospitals Act were presented to Parliament for debate. The Care and Coercion Bill [*Wetsvoorstel zorg en dwang*]⁶⁶ specifically caters for people with intellectual disabilities or dementia, while the Compulsory Mental Healthcare Bill [*Wetsvoorstel verplichte GGZ*]⁶⁷ is restricted to psychiatric patients. Both Bills claim to focus on good care, but by setting out very different sets of rules.

5.2. *Care and Coercion Bill*

The primary aim of the Care and Coercion Bill is to strengthen the legal position of clients with an intellectual disability or dementia.⁶⁸ The Bill sets out the procedures to be followed by care providers in the form of a multi-stage plan. Each stage of this plan has to be checked before providers are permitted to impose coercion. The care plan plays an important role, including in the care provided to involuntary patients. The Bill should also, however, take greater account of the special nature of these target groups, where care is long-term and where coercion is not unusual and can also be very invasive.

A special aspect of this Bill is that it has been designed for people of whom the majority are incapable of expressing their will. In our view, this starting point does not do justice to this target group as many clients with a (slight) intellectual disability can make their wishes known, admittedly in their own way. The Bill should take more account of this if it is to result in good care.

The Bill focuses on the issue of good care to a greater extent than the Psychiatric Hospitals Act does in that the emphasis is no longer on admissions. The Bill explicitly seeks to distance itself from the one-sided approach in the Psychiatric Hospitals Act (in other words, respect for the right of self-determination). The

⁶³ Act of 13 July 2002, *Bulletin of Acts and Decrees* 2002, 431, as amended by Act of 25 February 2008, *Bulletin of Acts and Decrees* 2008, 80, Articles 14a-14g.

⁶⁴ R.B.M. Keurentjes, *Rapport van de derde Evaluatiecommissie van de Wet Bijzondere opnemingen in psychiatrische ziekenhuizen. 1. Evaluatierapport: voortschrijdende inzichten*, (The Hague: Ministry of Health, Welfare and Sport, 2007), p. 106.

⁶⁵ *Parliamentary Papers II* 2007/08, 25 763, No. 9; *Parliamentary Papers II* 2007/08, 30 492, Nos. E and F.

⁶⁶ *Parliamentary Papers II* 2008/09, 31 996, No. 2.

⁶⁷ *Parliamentary Papers II* 2009/10, 32 399, No. 2.

⁶⁸ *Parliamentary Papers II* 2010/2011, 31 996, No. 6.

criteria for restraint are more broadly formulated, with danger as the norm being replaced by serious disadvantage.

The absence of good and clear legal protection, however, is a major failing. The Bill gives care providers more scope to structure ‘responsible care’ in the way they consider best.⁶⁹ The legislator does not stipulate who may restrict freedom and how this is permitted. In contrast to the Compulsory Mental Healthcare Bill, this Bill does not make provision for a confidential counsellor or for a court review or a decision by a committee in the event of involuntary care. Nor does it provide for close involvement of the Healthcare Inspectorate and/or a review committee. Moreover, all forms of restricting freedom are dealt with in the same way, regardless of whether they involve prohibiting a second cup of coffee or being kept in seclusion for three months.

In view of the right to development, the legislator could have been expected to consider long-term forms of freedom restriction particularly carefully. What is the added value of the new Bill for the client? Why has the legislator failed to make a distinction between restriction and restraint?

5.3. *Compulsory Mental Healthcare Bill*

This Bill aims to strengthen the legal position of people with a mental illness who receive involuntary mental healthcare.⁷⁰ According to the Dutch government, strengthening these people’s legal position will enhance the quality of care. To reach this goal, the Bill sets out a very elaborate procedure for authorizing ‘compulsory care’. Compulsory care can be authorized if a person has a mental illness that puts him at a ‘substantial risk of serious harm’ to himself or others. As explained in the notes to the Bill, this criterion should be interpreted in much the same way as ‘danger’ in the Psychiatric Hospitals Act. There seems, therefore, to be no intention to expand the grounds for involuntary mental healthcare.⁷¹ Contrary to the Psychiatric Hospitals Act, a court order is only needed if a patient (over the age of 12) or the patient’s legal representative actively resists mental healthcare. Compulsory care, however, is not restricted to involuntary admissions. A patient can also be required by court order to undergo treatment without being admitted to a psychiatric hospital. In fact, the Bill allows various forms of compulsory care to be authorized by a court, including pedagogical and safety measures. The Bill also introduced the concept of an independent committee of experts to advise the court on the form of care considered most effective for reducing the specific risk.

⁶⁹ B.J.M. Frederiks, “Compulsory care and coercion: a new Dutch Legal Framework for restraints in the care for people with an intellectual disability”, *Challenging behaviour & Mental Health, SIRG newsletter* (2010).

⁷⁰ *Parliamentary Papers II* 2009/10, 32 399, No. 3, pp. 1-2.

⁷¹ *Ibid.*, p. 42.

The Bill has a strong focus on avoiding involuntary mental healthcare. More so than the Dutch Psychiatric Hospitals Act, it focuses on the patient and on reaching agreement on the best possible care. Even in cases involving compulsory care, the patient's wishes and preferences are to be respected as much as possible. Here we can recognize the right to good care. The Bill also considers the right to development in that Article 3:3 includes the criteria of subsidiarity, proportionality and efficacy. Any compulsory care provided must meet these criteria. In other words, any restriction on freedom must serve a clear purpose. Another good point in the Bill is that Article 3:4 allows compulsory care also to be provided in order to stabilize a person's mental health or to allow a person's mental health to be restored to such an extent that he regains as much autonomy as possible. Here, too, we can recognize aspects of good care. The legislator goes further in this respect in this Bill than in the Psychiatric Hospitals Act, which is limited to preventing danger.

Although the above principles are to be applauded, field organizations and experts have justly criticized many of the rules contained in the Bill.⁷² For one, it was thought unnecessarily time-consuming and expensive for a patient to be heard and assessed both by an advisory committee and a court.⁷³ The government is consequently looking into other (cheaper) alternatives for the advisory committee.⁷⁴ The Bill also vests considerable power in 'care managers' to decide whether to impose compulsory care, without specifying the level of expertise required of these managers.

Apart from some — rather confusing — rules about representation, not much thought appears to have been given in the Bill to the legal position of children with psychiatric problems.⁷⁵ One of the main bottlenecks in child and youth psychiatry is that it is hard to establish whether a child is mentally ill and whether this means he represents a danger justifying compulsory admission and treatment.^{76, 77, 78} Although the Bill clarifies that compulsory care is also

⁷² See, for example, the letter of 6 February 2009 of KNMG, NVvP and NVVA (annex to *Parliamentary Papers II* 2009/10, 32 399, No. 3); also T.P. Widdershoven, "Opvolger Wet Bopz: goed op weg, maar we zijn er nog niet. Opmerkingen bij het conceptontwerp Wet verplichte geestelijke gezondheidszorg", *Tijdschrift voor Gezondheidsrecht* 33 (2009), pp. 175-184.

⁷³ J. Legemaate, "Besluiten over dwang in de psychiatrie: ken je klassieken!", *Nederlands Juristenblad* (2008), pp. 1852-1856; T.P. Widdershoven, "Dwangpsychiatrie: rechters, deskundigen, kwaliteit en geld", *Nederlands Juristenblad* (2008), pp. 1863-1864; J.R. van Veldhuizen, "Adviseren of beslissen? De positie van de Commissie Psychiatrische Zorg in de Wet Verplichte Geestelijke Gezondheidszorg", *Journaal Ggz en recht* (2009), pp. 155-171; and several articles in *Journaal Ggz en recht* 7(2) (2011).

⁷⁴ See J.R. van Veldhuizen, "Wat wordt er van de Wet verplichte ggz zonder een commissie?", *Journaal Ggz en recht* 7(3-4) (2011), pp. 63-68.

⁷⁵ V.E.T. Dörenberg, "Het Wetsvoorstel verplichte geestelijke gezondheidszorg", *Tijdschrift voor Gezondheidsrecht* 35 (2011), pp. 291-292.

⁷⁶ *Supra* note 7, pp. 185-188.

⁷⁷ *Supra* note 40, note 2.4.3, p. 43.

⁷⁸ B.M. Trooster, "De Wet Bijzondere Opnemingen Psychiatrische Ziekenhuizen (BOPZ)", in: N. Duits, J.A.C. Bartels and W.B. Gunning (eds.), *Jeugdpsychiatrie en Recht*, (Assen: Koninklijke Van Gorcum, 2004), pp. 323-324.

possible if a person's development is threatened, a link to an established mental disorder is still needed. The fact that parents are often also very ambivalent about agreeing to mental healthcare for their children continues to put pressure on relationships between care providers, children and parents, thus posing a risk in early treatment.

6. Conclusion

In the introduction we queried whether the right to self-determination was still the best principle in health law, particularly in caring for people with intellectual disabilities and children with psychiatric problems. We can be very brief in answering this question. The current legal framework focuses too much on the right to self-determination, with the legislator seeming to overlook the fact that the vulnerable position of these groups means they need more in order to be able to function in society. Both the recent case of Brandon and the current situation concerning children with psychiatric problems support this conclusion.

The right to development completes the normative framework for the legal position of people with intellectual disabilities and children with psychiatric problems. In the new Bills — the Care and Coercion Bill, and the Compulsory Mental Healthcare Bill — the legislator seems to have adopted a broader focus, with the right to good care and the right to development also being assigned a place. In this way the legislator seems to have moved away from the one-sided interpretation of self-determination. The ultimate aim in the care provided to people with intellectual disabilities and children with psychiatric problems is not their wish to be left alone, out of respect for their right to self-determination. They also want the right form of care and support in order to attain a meaningful place for themselves in society.

An issue briefly examined here is the question of why the legislator is seeking to provide different levels of protection for the two groups. Both groups are currently covered by the same legislation. In the new situation, however, the legal protection afforded to children with intellectual disabilities will be different from that available to children with psychiatric problems. Although the Care and Coercion Bill seeks to improve the legal position of people, including children, with intellectual disabilities, the Bill as it stands contains many legal shortcomings. Care providers, for example, are to be given responsibility for shaping certain aspects of the care as they see fit (under the heading of 'responsible care'). It would be advisable, however, for the legislator either to set the same rules and criteria for both groups or, if there are to be two different sets of regulations, at least to ensure greater coherence and equivalence. Although the Bills are certainly an improvement, in certain respects they also seem to represent a step backwards.

And this step backwards also has implications for elderly people. Firstly the Care and Coercion Bill is also intended to apply to people with dementia, who will now suffer the same (legal) shortcomings. Of much more importance,

however, is the fact that children with psychiatric problems grow old, while the life expectancy rates of people with an intellectual disability are increasing. If their legal position is not arranged properly at the start of their lives, this may have consequences for the care that they will be so much in need of in a later phase of life. And the question is whether this is really what society wants at a time when it already has to cope with an increasingly ageing population and ongoing cost cutting in the healthcare sector.