

## The Rights of People with an Intellectual Disability in the Netherlands: From Restriction to Development\*

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### Abstract

The purpose of this article is to discuss whether the right to self-determination<sup>1</sup> is the only and the best principle in health law for care providers to support their clients with an intellectual disability, or whether other principles such as the right to development, the right to good care and the right to protection might lead to a better protection of the rights of clients in this field of care. The right to self-determination is the central principle in the Dutch Psychiatric Hospitals (Compulsory Admissions) Act, which at times seems less than beneficial to the legal position of persons with an intellectual disability. The question is whether a new (alternative) legal framework, in which the focus shifts to the right to good care and the right to development, might improve the legal position of people with an intellectual disability.

### Keywords

legal position of people with an intellectual disability; freedom restriction; principles of health law; right to self-determination; right to protection; right to good care; right to development; Dutch Psychiatric Hospitals Act

### Introduction

Since the Nineties of the previous century, patients' rights have been of particular interest in the Netherlands. A great deal of legislation has come into force. The new Acts all share a central feature: they focus on the right to self-determination. This right, which is seen as one of the basic principles in health law, presupposes freedom: each individual has the right to decide how he shapes his life.<sup>2</sup>

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<sup>1</sup>) In this article the right to self-determination is considered as the basis of health law: it forms one of the main principles in this field of law.

<sup>2</sup>) Legemaate, J., Het zelfbeschikkingsrecht: een oud debat in nieuw licht, *Tijdschrift voor Gezondheidsrecht* (2004) 28, 18-20.

The right to self-determination is also well known in the care for people with an intellectual disability, even though some are actually unable to enjoy the right to self-determination. In the opinion of Leenen,<sup>3</sup> the right to self-determination is very important, and everything possible should be done to enable people to realise this right, taking into account the possibilities and limitations of people with an intellectual disability. This is not to say that Leenen underrates the importance of other principles of law. He endorses the view that the right to health care can make a substantial contribution when it comes to ensuring better chances for people to develop themselves.<sup>4</sup> The two principles — the right to health care and right to self-determination — are both needed: they are complementary in character.

However, there are dissenting voices about the actual meaning of this basic principle in health law, especially where it concerns the issue of self-determination by people with an intellectual disability. Among health law specialists it is sometimes thought that the equilibrium in health law is threatened by this emphasis on self-determination.<sup>5</sup>

A recent and ongoing discussion in the Netherlands illustrates this development. The issue is whether people with an intellectual disability are entitled to have children. The State Secretary for Health, Welfare and Sport responsible for this matter, stated that 'we are carrying things too far when we think the right to self-determination can be exercised by all in the same way'.

Although views differ in the Netherlands, in the Dutch health care system, the right to self-determination is still the main focus. An important Act is the Dutch Psychiatric Hospitals (Compulsory Admissions) Act, which has come into force in 1994. This Act, the Dutch Act on mental health, is not only relevant to psychiatry and psycho-geriatrics, but also to the care for people with an intellectual disability. It allows care providers to apply freedom restriction, but only when certain conditions are met. As the central feature of the Dutch Psychiatric Hospitals Act is the right to self-determination, a care provider is allowed to intervene in the life of a client only when special conditions apply. The key question here is whether care providers, based on the characteristics of the Act, are able to support clients in such a way that the client's abilities may be developed and that good care<sup>6</sup> is taken into account.

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<sup>3</sup> Leenen, H.J.J., *Handboek gezondheidsrecht, Deel 1 Rechten van mensen in de gezondheidszorg*, vierde herziene druk bewerkt door H.J.J. Leenen en J.K.M. Gevers, Houten/Diegem: Bohn Stafleu Van Loghum 2000, p. 32.

<sup>4</sup> *Ibid.*, p. 25

<sup>5</sup> Hendriks, A., *In beginsel. De gezondheidsrechtelijke beginselen uitgediept*, Leiden: Stichting NJCM-Boekerij 2005, p. 11.

<sup>6</sup> The principle good care is based on article 22 (1) of the Dutch Constitution and laid down in a number of patient's rights Acts: article 2 Care Institutions (Quality) Act, article 40 (1) Individual Health Care Professions Act and article 7:453 Civil Code on good care providership.

The subject to be discussed therefore is whether the right to self-determination is the only and the best principle in health law<sup>7</sup> for care providers to support their clients with an intellectual disability, or whether some other principles such as the right to development, the right to good care and the right to protection might lead to a better protection of the rights of clients in this field of care. This is not to say that caregivers completely neglect the other principles. However, the general focus is still too much on the right of self-determination and for the greater part, on the right to protection.

The four principles are all explored briefly in section two. This exploration will provide a background framework for analyzing, in section three, the Dutch Psychiatric Hospitals Act. Some aspects of the Act do not seem to protect the rights of clients with an intellectual disability adequately in the Netherlands, at times they even seem to harm the client. After reflecting on the principles of this Act, the focus will be on a proposed new legal framework for clients who have an intellectual disability and need some kind of support, which may lead to freedom restriction from time to time. An important element of this alternative legal framework is the right to development.

## 1. Principles of Health Law

### 1.1 *The Right to Self-determination and the Right to Protection*

The main principles of health law in the care for people with an intellectual disability are the *right to self-determination* and the *right to protection*. They are the ones usually mentioned in relation to the rights of clients.<sup>8, 9</sup> Other principles, which are discussed later on in this section, are rather more in the background.

In the care for people with an intellectual disability everything possible should be done to respect the client's right to self-determination. There is a real danger that clients are not allowed to take their own decisions, just because they have a 'handicap'. However, we should not allow anyone to put aside this right too quickly. The right to self-determination is not the only principle that counts in the care for people with an intellectual disability. The right to self-determination and the right to protection are two sides of the same coin: the protection principle expresses itself in the restriction of the exercise of the right

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<sup>7</sup> Hendriks, A., In beginsel. De gezondheidsrechtelijke beginselen uitgediept, Leiden: Stichting NJCM-Boekerij 2005, p. 7: 'Zelfbeschikking vormt volgens veel gezondheidsjuristen een belangrijk, zo niet het belangrijkste patiëntenrecht'.

<sup>8</sup> Ibid., pp. 5-11

<sup>9</sup> In the field of ethics a great deal of attention is paid to self-determination: Beauchamp, T.L. en J.F. Childress, Principles of Biomedical Ethics, New York/Oxford: Oxford University Press 1983 and I. Berlin, Two concepts of Liberty, Oxford: University Press 1958.

to self-determination.<sup>10</sup> It is difficult to find a good definition of the right to protection in legal literature. In practice the principle means that a client may be restricted in his freedom in order to provide him with optimum protection. As things stand, the object of protecting clients is restricted to protecting the client against himself. This narrow description of the principle of protection indicates that protection is allowed in the interest of the client only. Basically, it is unacceptable to take measures to protect a client for any reason not immediately linked to that client. Staff shortages, unqualified staff, the way the institution is built, or client overcrowding: none of these is in itself a valid reason to protect a client against himself. Reasons like these do not justify restricting a client's freedom. An exception may be made only in situations where the common good or third parties are in danger. A care provider has to deal with these limitations. They mean, more or less, that the right to self-determination is not limitless; the boundaries apply to every citizen in our society. However, infringement of the right to self-determination is allowed only when there is no adequate — less intrusive — alternative, and provided the balance between the object of the infringement and its consequences is proportional, and the infringement is stopped the very moment the necessity for it no longer exists.

The client's vulnerable and dependent position demands legal protection. It is the responsibility of the law to safeguard the legal position of clients. In the care for people with an intellectual disability however, this should not be the only function of the law. Every client, within the scope of his abilities, ought to have the chance to live his life according to his own views. Therefore it is also up to the law to ensure that the client's right to self-determination is respected, and if possible, promoted. Clients have their own abilities and wishes and may prefer care providers not to intervene, instead of protection. However, many clients with an intellectual disability lack the capacity to make independent decisions and are unable to live their life without some assistance from care providers. Care providers who, although they may have the very best intentions, do not acknowledge this 'incapacity' of clients, may not provide good care and much more seriously, they possibly do not respect the legal position of their own clients. This may even constitute a real risk to clients with an intellectual disability: clients are sometimes left alone unless they explicitly ask for help and in this way they may not receive the care they need. This situation is just another illustration of the strong link between the rights of self-determination and protection.<sup>11</sup> The care for people

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<sup>10</sup> Frederiks, B.J.M., *De rechtspositie van mensen met een verstandelijke handicap. Van beperking naar ontplooiing* (diss.), Den Haag: Sdu Uitgevers BV 2004, p. 94.

<sup>11</sup> Klippe, C.J. van de, *Dwangtoepassing na onvrijwillige psychiatrische opname* (diss. Amsterdam UvA), Nijmegen: Ars Aequi Libri 1997 and Frederiks, B.J.M., *De rechtspositie van mensen met een verstandelijke handicap. Van beperking naar ontplooiing* (diss.), Den Haag: Sdu Uitgevers BV 2004, p. 75 en 94.

with an intellectual disability is not just about the right to self-determination: the right to protection is equally important.

## 1.2 *A Case*

Recently an incident caused quite a stir in the Netherlands. In a home for the elderly a 56-year-old man was found in his room where he had died two to three days earlier. He had been living in the home for almost 10 years and in his opinion he did not need any care. He lived completely independently in his room and did not want any contact with others, care providers included. Management and care providers respected his wish. This occurrence could also have taken place in a home for people with an intellectual disability, particularly when clients live semi-independently in sheltered accommodation with little supervision. Here, the same issues around 'self-determination' are being discussed.

An important question in this discussion is to what extent care providers should respect a client's right to self-determination; and to what extent management remains responsible for the well-being of a client when that client wishes to be left alone. From the point of view of respect for the client's self-determination, the home for the elderly had acted correctly. Looking beyond the right to self-determination, other principles such as providing good care come into the fore. These will be discussed in section three and beyond.

All too often the legal position of clients with an intellectual disability is viewed from a (too) narrow perspective: either exclusively from the perspective of providing protection for the client, or exclusively from the perspective of encouraging self-determination of clients. Recently this opposition of views has been abandoned. The right to self-determination is no longer seen as the right to be left alone.<sup>12</sup> Among human rights lawyers thought the view still prevails, unfortunately, that intervention by the state in the broadest sense needs to be restricted as much as possible.<sup>13</sup> It is especially in the care for people with an intellectual disability that this position should not always, and not entirely, be the focus. It is much more important to develop and secure the rights of clients with an intellectual disability, and therefore a combination of principles should apply. The care provider who aims to develop the possibilities of a client should look for the best possible mix somewhere between protection and self-determination.<sup>14</sup> The same idea is to be found in the field of ethics. In this discipline, a solution is looked for in the concept of 'relational autonomy,' which is less about non-intervention by

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<sup>12</sup> Frederiks, B.J.M., *De rechtspositie van mensen met een verstandelijke handicap. Van beperking naar ontplooiing* (diss.), Den Haag: Sdu Uitgevers BV 2004, pp. 101-103.

<sup>13</sup> Ozdowski, O.A.M., *Human rights for people with intellectual disabilities in Australia: where to from here?* Inclusion International 13th Congress, Melbourne 24 September 2002.

<sup>14</sup> Frederiks, B.J.M., *De rechtspositie van mensen met een verstandelijke handicap. Van beperking naar ontplooiing* (diss.), Den Haag: Sdu Uitgevers BV 2004, p. 75.

care givers than about increasing the client's freedom of action and freedom of choice. Therefore the important question is not just whether the client is able to make an independent choice, but also what he is able to accomplish by making that choice. From the care giver this requires a different attitude which is elaborated in the description of the concept of good care.<sup>15</sup>

In addition to the right to self-determination and the right to protection, two other principles are of major importance with respect to the legal position of clients with an intellectual disability: *the right to good care* and *the right to development*.

### 1.3 *The Right to Good Care*

The right to health care is laid down in article 22 (1) of the Dutch Constitution and is a social human right. Good care is based on this right, but as, in many ways, it shows the characteristics of an individual right, it may be compared to the right to self-determination. It is an accentuation of the right to health care that consists of three elements: quality of care, geographical accessibility of care, and financial accessibility of care. In good care, the emphasis is in particular on the provision of care of a good quality, and less on the elements of availability and accessibility of care.

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'.<sup>16</sup> To be able to offer this client-centred care, the care provider — who is often a personal coach — should possess certain qualities. The care provider should be able to provide care in a transparent way and be accountable for his actions to third parties. Also, he should be able to empathise with the client as to the situation the client is in, in order to be able to contribute to the development of the client. From this point of view, care can be seen as offering support to clients. In the modern interpretation, care is in many ways similar to support. Here, the emphasis is no longer on what the client is unable to do, but on empowering the client. In the modern care for clients with an intellectual disability, the care provider aims to support clients in dealing with choices and he may question choices a client makes. It is considered the care provider's responsibility to be understanding and committed to help the client to go forward. These are some of the characteristics of good care.<sup>17</sup> The right to good care is a special principle of law in this respect that it allows room for self-determination as well as protection (see at the end of this section a scheme with the main four principles). Both elements are

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<sup>15</sup> Hooren, R.H. van et al., 'Autonomy and intellectual disability', *Journal of Intellectual Disability Research* (46) 2002-7, pp. 560-568.

<sup>16</sup> Frederiks, B.J.M., *De rechtspositie van mensen met een verstandelijke handicap. Van beperking naar ontplooiing* (diss.), Den Haag: Sdu Uitgevers BV 2004, pp. 101-106.

<sup>17</sup> Widdershoven, G., Berghmans, R.L.P. and Welie, S.P.K. "Zelfbeschikking of goede zorg? Ethische kanttekeningen bij juridisering in de hulpverlening", in: Schene, A.H. e.a., *Jaarboek voor psychiatrie en psychotherapie*, Houten/Diegem: Bohn Stafleu Van Loghum 2003, pp. 325-338.

crucial for the development of clients with an intellectual disability. The principle good care can allow for a client's freedom to be restricted at times while at others there is more scope for the client's activities. It is up to the care provider to assess, in consultation with the client or his representatives, the client's current possibilities. In some cases however, it is unavoidable to protect a client against himself. However minor the restriction of freedom may be, it does constitute a breach of the client's freedom. It is therefore essential that such breaches are reduced to the minimum. Good health-care providership, which is laid down in the Dutch Civil Code,<sup>18</sup> does not imply that the care provider is almost never allowed to intervene in the life of a client. It is more than non-intervention and an attitude of aloofness towards the client. The role expected of a care provider is an active one. His actions should be geared towards stimulating the abilities of a client. Instead of focusing on 'non-intervention', it is preferable to focus on 'support where possible and necessary'. As this approach may slide in the direction of paternalism, it is essential that the care provider is transparent in his actions and accountable to third parties. An important element of good care is that the care is aimed at furthering the development of clients as much as possible.

#### 1.4 *The Right to Development*

In the care for persons with an intellectual disability, with an eye to the specific position of individuals with an intellectual disability, the emphasis should be (more) on *the right to development*. Clients with an intellectual disability often stay in institutions or other forms of sheltered housing for very long periods of time, and often from a very early age. It is of great importance that the client's development does not stagnate during this stay. Every client, whatever the degree of his disability, has some possibilities, which can be developed.

For some time now, the right to self-determination has been applied as a principle of law in care for the young.<sup>19</sup> In the past the young were predominantly seen as an object of care, with the care centring on treatment and protection. Increasingly, the emphasis in this sector has shifted from protection to development. A similar change of perspective is taking place in the care for those with an intellectual disability in the Netherlands. In the context of the (full) member of civil society paradigm,<sup>20</sup> clients should have the opportunity to gain experiences

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<sup>18</sup> Article 7:453 Dutch Civil Code.

<sup>19</sup> Langen, M. de, *Recht voor jeugdigen: een onderzoek naar rechten en rechtsbeginselen in het jeugdrecht* (diss. Utrecht), Alphen aan den Rijn: Samsom Uitgeverij 1973, p. 16.

<sup>20</sup> A civil society paradigm can be seen as a society in which persons with an intellectual disability have the same possibilities as other citizens. Support plays an important role in this society: people with an intellectual disability receive support to such an extent, that, notwithstanding their limitations, they are able to function as much as possible like another (able) citizen in society. Gennep, A.Th.G. van en Hove, G. van, *Zijn het burgerschapsparadigma en inclusie dan niet bruikbaar voor mensen met een ernstige verstandelijke handicap? Kanttekeningen bij een zorgelijke ontwikkeling*, *Nederlands Tijdschrift voor de Zorg aan verstandelijk gehandicapten* (26) 2000-4, p. 252.

in order to be able to further their development. Article 23 of the Convention on the Rights of the Child states that, whenever possible, every child with an (intellectual) disability should have the appropriate support needed to further his self-reliance. This article also seems to have relevance for adults with an intellectual disability. Every person with an intellectual disability should have a right to appropriate support if necessary, whether adult or child. Being of age is by no means an indication that a client no longer needs some kind of support.

A similar, but also different approach, can be found in the recently adopted United Nations Convention on the Rights of Persons with Disabilities. In this Convention the ultimate goal of support is 'autonomy' and 'independence'. In the preamble is stated that the States Parties have to recognise the individual autonomy and independence of persons with an intellectual disability.<sup>21</sup> Respect for autonomy is also mentioned in the general principles and includes the freedom to make one's own choices and independence of persons.<sup>22</sup> Autonomy is, however, not the only guiding principle in supporting persons with an intellectual disability. The Convention also acknowledges the close relationship between autonomy and care. Autonomy, depending on the possibilities of a client, which is called in the Convention 'their maximum independence', can only be realised if clients have an everlasting right to good care. In article 25 is stated that 'persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination (...)'.<sup>23</sup>

The right to self-determination completes the normative framework for the legal position of persons with an intellectual disability. It can be realised by offering clients the right combination of protection and self-determination. For clients with an intellectual disability this is the only possible way to attain an optimum development of his possibilities. The best mix of rights may be deduced from the principle of law 'good care' that ought to be an ideal combination of the two other principles: those of protection and of self-determination. It presupposes the care giver's commitment, support and protection where necessary.<sup>23</sup>

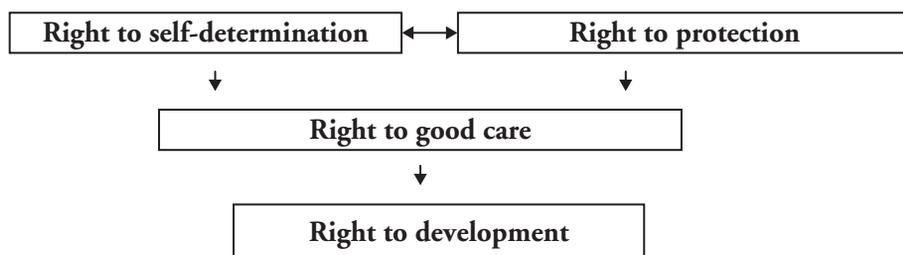
Moreover, keeping in mind good care, it is important that any freedom restriction should, if possible, contribute to the client's development. Of course, this aim is not always attainable. The boundaries of the right to self-determination — the common good and third parties — have always to be taken into account. This means that it is not always possible to develop a client's capacities. Nevertheless, the statement may be defended that in the care for people with an intellectual

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<sup>21)</sup> United Nations Convention on the Rights of Persons with Disabilities. Preamble, the States Parties to the present Convention 1) recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.

<sup>22)</sup> Article 3: the principles of the present Convention shall be a) respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.

<sup>23)</sup> Frederiks, B.J.M., *De rechtspositie van mensen met een verstandelijke handicap. Van beperking naar ontplooiing* (diss.), Den Haag: Sdu Uitgevers BV 2004, pp. 111-114.



*Normative framework for the legal position of people with an intellectual disability*

disability, care providers usually decide to protect clients, instead of offering them more opportunities. Care providers try their utmost to prevent a client's actions causing damage to him and others including other clients and health care professionals. However, taking into account the other three principles of health law as well, there is only room for infringing the right to self-determination when there is no adequate alternative, and when there is a reasonable proportion between the object of the infringement and the consequences of it, and the infringement is stopped the very moment the necessity for it no longer exists. Only then it is within reach to emphasise the right to development of clients as much as possible.

In contrast to some other countries such as Australia, the right to development is not explicitly mentioned in any Dutch Act. Article 22 (3) of the Dutch Constitution states: The authorities shall promote the social and cultural development and leisure activities. Unfortunately the text is rather vague, and in itself the article is not enough to base a claim upon: the article is directed to the authorities. In order for an individual client to be able to claim a right to development, such a right would have to be anchored in specific legislation. Furthermore, a client's development, which is the issue here, is not just about participation in cultural events and recreation. It is important that clients get the opportunity to participate fully in the community without any prejudices.

*1.4.1 Right to Development in Other Countries*

Currently, there is no article in Dutch legislation which states, emphasises and guarantees that persons with an intellectual disability should have the opportunity to develop themselves in every area, nor is such a right to be found in international and European treaties.

However, some countries do have such legislation, Australia for instance. The Intellectually Disabled Persons' Services Act (1986, amended 12 December 2005), which, due to the federal system in Australia applies only to persons with an intellectual disability who live in the State of Victoria, contains a long list of principles, including one about development. One of these is the following: 'every intellectually disabled person has a capacity for physical, social, emotional and intellectual development and a right to individualised educational and developmental

opportunities and is entitled to exercise maximum control over every aspect of his or her life'. In part two of the Act the aim and objectives of the Department of Human Services are stipulated. The primary aim is to advance the dignity, worth, human rights and full potential of intellectually disabled people. The development of persons with an intellectual disability forms a central element of the policy of the Department.

This brief exploration of the four main principles for health law gives us an outline background framework for analyzing the Dutch Psychiatric Hospitals Act. Two individual cases will show why the protection of the rights of clients with an intellectual disability may be improved in the Netherlands. This is especially the case in situations where the client's freedom is restricted.

## **2. Freedom Restriction in the Care for People with an Intellectual Disability**

In the Netherlands, but also elsewhere, the starting-point in the care for people with an intellectual disability is that freedom restriction should be limited to the minimum. This attitude is based on the idea of the right to self-determination, which plays an important role in the field of health care. Measures of freedom restriction include not only restraint, seclusion, or the forced administration of drugs, but also limiting a person's freedom, for instance by forbidding him or her to go out or to go cycling.

The application of freedom restrictions in the care for people with an intellectual disability cannot be prevented completely, especially when a care provider wants to provide 'good care' to their clients. This dilemma used to be viewed from a narrow perspective: it should either provide protection for the client or stimulate the client's self-determination. Two cases referred to below show us that working out this dilemma is not always easy. A care provider has to deal with a number of serious questions. Two important aspects that keep returning are the necessity of the intervention and the search for a better alternative.

### *2.1 Two Cases*

#### Case 1

A 24-year-old client, with a moderate intellectual disability, lives in an intramural institution for the care for people with an intellectual disability. She has a mild form of epilepsy, and she likes to walk. This implies a danger of occasionally falling to the ground. The care provider wants to avoid unnecessary risks. When at times things are too hectic in the home, she is fixed to her chair. The client's parents oppose this policy: they prefer their daughter to be free and they accept that this freedom has some accompanying risks. A solution was found in a crash helmet, which the client wears continuously during the day.

## Case 2

A 50-year-old client with a minor intellectual disability lives on her own in an apartment that belongs to a large institution nearby. She receives a few hours of support during the day. In recent years she has been showing some symptoms of dementia. At night she wanders around in her home, and she has also gone out into the street a few times. Her coach proposes to lock her front door during the night, to prevent her from going out. Another option that is being considered is to relocate her. In an institutional setting it would be more convenient to apply measures.

In both cases the care provider has to make a choice: does he choose freedom restriction (the easier option in Case 1) or does he look for alternatives. The circumstances described in Case 1 allow enough room for a care provider to find alternatives. The question arises why the realisation of risks of epilepsy should be prevented in persons with an intellectual disability in particular. A person with epilepsy who is not institutionalised runs various risks, which he may decide, either to run or to prevent. However, the situation is different for a client who is unable to make this kind of decision for himself and who is institutionalised. The institution is responsible for the client's safety, especially where relatively simple preventive measures are possible. Therefore a client who is admitted in an institution, is often restricted in his freedom 'at an earlier stage' than someone who is not.

It is obvious that good care does not mean restricting the freedom of a client because things getting 'too hectic' in a house, nor that all risks should be banned. The care provided in Case 1 would seem to fall short of good care. The right to development can only be realised by offering clients the right combination of protection and self-determination. In Case 1, the care provider fails to offer a mixture of both aspects: apparently, freedom restriction to him seemed to be the only available option. Case 2 is a different story. Restricting the client to the apartment means she will not have to move back into an institution, and so this restriction will, hopefully, benefit her development. In an institution she will have far less freedom: less freedom than is appropriate and desirable in her situation.

The Dutch Psychiatric Hospitals Act is the legal framework that applies in both cases. It allows care providers to apply freedom restriction, but only if several conditions are met. One important condition is that the client constitutes a danger to himself or to his environment that is caused by the intellectual disability. In jurisprudence this danger criterion is rather narrowly interpreted. According to Dutch courts, the fact that a client does nothing but shout, or is unable to sit still during meals, does not provide a sufficient reason to apply freedom restriction, for instance seclusion in the client's own room.

In addition, the concept of the actual freedom restriction is narrowly defined as well. Some ways of restricting clients' freedom are not covered by the definition, such as influencing a client, offering a client a learning course or administering a sanction. This, however, does not mean that these restrictions, which frequently

limit the freedom of clients, are not applied in daily practice. In England and Finland for instance these restrictions are called 'subtle forms of coercion'. In Finland there is a large 'grey zone' of measures that also do not fall within the ambit of the Mental Health Care Act.<sup>24</sup> In England clients have to deal with 'informal measures'.<sup>25</sup> These measures, which may have different labels but they still restrict the freedom of clients, are similar to some measures in the Netherlands. They are neither recognised nor reported as freedom restriction.

Research has shown that care providers in the Netherlands offer clients with an intellectual disability the support they think is appropriate.<sup>26</sup> The problem is that many of the measures they apply are, strictly speaking, forbidden as they are not applied in order to prevent an acute danger but for other reasons. In the context of care for people with an intellectual disability such measures are about making various agreements with clients, setting up learning paths, offering perspective and enhancing and coaching the way the client is functioning (in the context in which he lives). From the point of view of good care, care providers consider these measures to be necessary, and they apply them — notwithstanding the current legal framework. And the problem is that care providers are not always aware that these measures can in fact be viewed as freedom restriction.

The cases above illustrate how complex this concept of providing good care actually is in the care for people with an intellectual disability. The sector does subscribe to the principles of the Dutch Psychiatric Hospitals Act (providing protection and self-determination). The problem is that care providers find it difficult to work in accordance with the very strict principles of the Psychiatric Hospitals Act. They feel that in many situations they are not allowed to intervene, because of the narrow framework of the Act, which allows freedom restriction only in situations of danger to the client or to others. This principle forces care providers to make an intervention on a temporary basis only: the measure has to be concluded as soon as the danger is gone. Acting this way does not tally with delivering good care to clients. The emphasis on elimination of danger is too narrow in the care for the intellectually disabled. Personal coaches see their work in terms of protecting, educating and proceeding in an educational way. These terms do not feature in the Psychiatric Hospitals Act. As a result, care providers act outside the legal framework in order to offer good care to clients.

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<sup>24</sup> Stoor, H. *Regulating Coercion — Experiences of the 2001 Reform of the Mental Health Care Act in Finland*, 16th World Congress on Medical Law, August 11th, 2006, Toulouse, France 2006.

<sup>25</sup> Mental Health Act Commission (2005) <http://www.mhac.org.uk/Pages/documents/publications/MHAC%2011%20TEXT%20FA.pdf>

<sup>26</sup> Frederiks, B.J.M., *De rechtspositie van mensen met een verstandelijke handicap. Van beperking naar ontplooiing* (diss.), Den Haag: Sdu Uitgevers BV 2004 en Abma, T.A., Frederiks, B.J.M., Hooren, R.H. van, Widdershoven G.A.M., Wijmen, F.C.B. van, en L.M.G. Curfs, *Kwaliteitscriteria voor vrijheidsbeperking in de zorg voor mensen met een verstandelijke beperking*, Maastricht: Universiteit Maastricht 2006

In the next section the advantages and disadvantages of an alternative legal framework for the care for people with an intellectual disability are discussed. This framework emphasises the right to self-determination, but also the right to good care, which consists of the right to protection *and* self-determination, and the right to development.

### **3. An Alternative Legal Framework for the Care for People with an Intellectual Disability**

An important aspect of an alternative legal framework for the care for people with an intellectual disability should be that the client's self-determination (autonomy) is no longer the key. Care providers do not like the idea of leaving their clients 'alone'. They think and feel that they have to stimulate and develop the clients' possibilities. This new legal framework could also be used for the application of freedom restrictions and should eventually lead to an alternative Dutch Psychiatric Hospitals Act. If self-determination were no longer the main health law principle in the care for people with an intellectual disability that could also mean that criteria such as 'danger' and 'freedom restriction' would have to be viewed from a broader perspective.

#### *3.1 Main Principles*

The main principles of an alternative legal framework should be, in addition to the right to self-determination, the rights to good care and legal protection. The latter two principles are currently undervalued in the present Dutch Psychiatric Hospitals Act. On the one hand, there is room for improvement in the care clients currently receive and on the other hand they are insufficiently protected against freedom restriction, whether legal or illegal.

Although the scope of the alternative regulation would be much broader than that of the Psychiatric Hospitals Act, the application of freedom restriction would remain an *ultimum remedium*. The application of freedom restriction should be acceptable only when the criterion of necessity is met. Necessity in this context is viewed as necessary to the client himself. In principle, factors outside the client should not be part of the criterion. Necessity, however, should leave room for 'danger to others' (see section 1). In this sense the freedom restriction does not directly contribute to the well-being and the development of the client, but third parties are being protected. It is important to assess whether the measure is effective, is in proportion to the intended goal, and cannot be replaced by a reasonable alternative that is less intrusive in character. During the execution of any measure there are several ways in which the care provider may contribute to the client's development (keeping in contact with the client at all times, looking for alternatives, ending the measure as soon as possible).

An alternative regulation should taken into account specific characteristics of the sector of care for the intellectually disabled. This will not prevent a number of critical comments to be voiced about the contents of the regulation. However, the interests at issue in this sector are such, that they do justify separate regulation for a number of reasons. Clients in this sector are usually less competent and, unlike clients in psychiatric and psycho-geriatric institutions, they are often confronted with (serious) forms of freedom restriction during much of their life. It is especially this reason that justifies the introduction of an alternative legal framework for clients with an intellectual disability. Everything should be done to protect *and* develop the rights of those clients.

#### 4. Conclusions

Some of the following conclusions and recommendations may be seen in a broader context. Not only care providers in the Netherlands, but also care providers in other European countries such as Finland and England, struggle with the rights of vulnerable patients and especially with the issue of 'freedom restriction'. In these countries the right to self-determination is also a central principle in health law.

The care for persons with an intellectual disability should be provided with another perspective in mind. That 'other perspective' should include the introduction of the right to development and the significance that this perspective can have for clients with an intellectual disability. In section one and two was stated that this right to development is better suited to the characteristics of the care for people with an intellectual disability. When in addition the right to good care is included, this would lead to a broader legal framework without the limitations of the current legal framework in the care for persons with an intellectual disability.

Although it seems that the right to development is completely new in the care for persons with an intellectual disability, the example of Australia and also the new Convention proves that it is not. Both the Parliament and the Department of Human Services of the State of Victoria consider the development of clients as a central element in their legislation. In the current Dutch legal framework no adequate attention is paid to the characteristics of the sector of care for the intellectually disabled, and this leads to care providers evading the rules. Under the Dutch Psychiatric Hospitals Act care providers are unable to offer clients the appropriate support and are therefore at times unable to deliver good care. Care providers are expected to be transparent in their actions, and it is important that they are able to indicate the reason for a client being restricted in his freedom. The only legitimate reason ought to be the encouragement of the client's development.

The ultimate goal of the alternative legal framework should be in creating more freedom and choices for clients with an intellectual disability, but always from the

starting point of providing good care. Leaving a client to himself without really listening to his wishes is not the best example of respecting the rights of clients. As a consequence, the current basic principle, the right of self-determination (autonomy), should no longer be the focus. Self-determination does not necessarily lead to good care in the care for the intellectually disabled. The objective of providing good care is to offer perspective to clients. Through the right form of support, of which freedom restriction can be an element, the client's abilities can be developed.

As with all complex issues, discussion is possible on the basic principles in the case of freedom restriction. When it comes to application of freedom restriction, a great deal of discussion on the basic principles in the various legal systems is still ahead of us. This does not only count for people with an intellectual disability but for people with dementia and psychiatric disabilities as well. They also have a right to good care and self-determination. An important question is whether respecting the right to self-determination in those fields of care will guarantee both elements to them. In the Netherlands psychiatrists and politicians would like to broaden the possibilities of compulsory treatment, especially when it concerns patients who are involuntary admitted. They believe that these adjustments will lead to 'a repaired balance of the autonomy of the patient and the need of treatment'.<sup>27</sup>

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<sup>27</sup>) Kamerstukken II 2005-2006, 30 492, Wijziging van de Wet Bijzondere opnemingen in psychiatrische ziekenhuizen (voorwaardelijke machtiging en dwangbehandeling). Nota naar aanleiding van het verslag.