



## VELFERÐARRÁÐUNEYTIÐ

*Ministry of Welfare*

### **Act on the Protection of the Rights of Disabled Persons, No. 88/2011, with subsequent amendments under the Acts No. 126/2011, No. 59/2012, No. 84/2015 and No. 115/2015.**

#### **Chapter I**

##### **General provisions.**

###### Article 1

###### *Scope and aim.*

[This Act shall apply to the protection of the rights of disabled persons.]<sup>1)</sup>

The provisions of Chapter IV shall also apply to the protection of the rights of individuals who, as a result of chronic illness or accidents, need support in preparing to take an informed decision on their personal affairs, or assistance in securing their rights, whether this is vis-à-vis public service providers, other government agencies or private entities.

[The aim of this Act is to ensure disabled persons appropriate support in the defence of their rights and to ensure that disabled persons' right of self-determination is respected and that in cases where it becomes a matter of urgent necessary to intervene in their affairs, this will be done in full compliance with their security under law.]<sup>1)</sup>

In the application of this Act, the United Nations' Convention on the Rights of Persons with Disabilities shall be taken into account.

<sup>1)</sup> Act No. 59/2012, Article 1.

###### Article 2

###### *Supervision.*

[The minister]<sup>1)</sup> shall be in charge of the protection of the rights of disabled persons under this Act.

<sup>1)</sup> Act No. 126/2011, Article 549.

#### **Chapter II**

##### **[The ministry's rights monitoring unit.]<sup>1)</sup>**

<sup>1)</sup> Act No. 126/2011, Article 549.

###### Article 3

[The ministry shall supervise disabled persons' rights and shall set up a special rights monitoring unit within itself.]<sup>1)</sup>

The role of the rights monitoring unit shall be:

- a. to monitor the work of rights protection officers for disabled persons and give them advice and guidance as needed,
- b. to gather data on matters relating to disabled persons' rights and developments in ideology and services to the disabled and to put forward recommendations on improvements,
- c. to be responsible for educational and publicity work, in collaboration with [disabled persons' interest groups]<sup>2)</sup>, regarding disabled persons' rights, e.g. for disabled individuals, their rights protection officers, their spokesmen and relatives or persons responsible for them and for workers and service-providers,
- d. to monitor new developments in ideology and services to the disabled which could result in improved services and an enhanced quality of life for the disabled,
- e. to undertake the publication of easy-to-read materials and booklets on disabled persons' rights,

- f. to be responsible for educational and publicity work in collaboration with, and in consultation with, [disabled persons' interest groups]<sup>2)</sup> in order raise public awareness of disabled persons' rights, work against stereotyped ideas and prejudices and increase awareness of disabled persons' capacities and the contribution they can make.

<sup>1)</sup> Act No. 126/2011, Article 549. <sup>2)</sup> Act No. 115/2015.

### **Chapter III** **Rights protection officers for disabled persons.**

#### Article 4

Regional rights protection officers for disabled persons, whom the minister shall engage after receiving the comments of the national disabled persons' organisations, shall operate throughout Iceland. A condition for engagement as a rights protection officer shall be the possession of knowledge and experience of disabled persons' affairs and rights. Efforts shall be made to engage rights protection officers who have educational qualifications which will be of use to them in their work.

Rights protection officers may not, concurrently with their work as such, work for a service provider in the service region in question in positions that are incompatible with their work as rights protection officers.

The minister shall issue a regulation<sup>1)</sup> on rights protection officers for disabled persons, including provisions on their number.

<sup>1)</sup> Regulation No. 973/2012, cf. No. 63/2014.

#### Article 5

Rights protection officers shall monitor the circumstances of disabled persons in their regions and be available to assist them in securing their rights of any type, whether these concern the handling of their personal finances, the services to which they are entitled or other personal rights or personal affairs.

Where a disabled individual lives in a home for the disabled, the director of the home shall provide the rights protection officer with the information he/she needs for his work. In the case of information about personal matters or disabled persons' personal finances, the disabled individual's permission, and that of the individual's personal spokesman, shall be sought where such a personal spokesman exists, cf. Chapter IV.

#### Article 6

All persons shall be obliged to notify a rights protection officer if they have reason to believe that a disabled individual's rights are being violated. Disabled individuals' relatives or persons responsible for them, personal spokesmen, service providers, disabled persons' organisations and others who, through their position, connections or work, become aware that the disabled individuals' rights are not being respected, shall report this to a rights protection officer. A disabled individual who considers that his rights are not being respected may report this to the rights protection officer in the region in question. The rights protection officer shall give the disabled individual the support necessary in order to investigate the matter in consultation with him/her. The rights protection officer may also, at any time, take a matter up at his/her own initiative. If a rights protection officer comes to the conclusion that a disabled individual's rights have not been respected, he/she shall help the disabled individual to pursue his/her rights, taking into account the circumstances in each particular case and the disabled individual's wishes.

If the rights protection officer considers a case to be of such a nature, and after obtaining the approval of the disabled individual, the rights protection officer may deliver to the party concerned instructions on how to remedy the situation, giving him a deadline by which these are to be complied with. If the remedial instructions given by the rights protection officer are not acted upon, and he/she considers that the matter may be made the subject of a complaint to the Social Services and Housing Affairs Complaints Committee, he/she shall help the disabled person to submit a complaint and help him/her with the conduct of the case if requested to do so.

The rights protection officer shall assess, in each case separately, in collaboration with the disabled individual, whether the matter should be reported to the ministry.

## **Chapter IV**

### **Disabled persons' personal spokesmen.**

#### Article 7

Disabled individuals who ...<sup>1)</sup>, due to their disabilities, have difficulty defending their interests, shall be entitled to personal spokesmen. Disabled individuals shall choose their own spokesmen, and may ask to consult a rights protection officer in the region in question regarding their choice. The rights protection officer [and as appropriate legal guardian]<sup>1)</sup> shall confirm the individual's choice of spokesman. If the disabled individual is unable, in the opinion of the rights protection officer, to express his/her wishes on this matter, the individual's next of kin or persons responsible for him/her shall be consulted. The disabled individual and his/her personal spokesman shall sign an agreement covering the assistance, which shall be kept by the rights protection officer. If the disabled individual is not able to sign the agreement, exemption may be granted from the signature requirement; in such cases, the agreement shall be made in the presence of the rights protection officer and in accordance with rules subject to further provisions to be laid down in a regulation.

The personal spokesman shall have a knowledge of the personal requirements and fields of interest of the individual whom he assists. The personal spokesman shall receive information and guidance on the content and priorities in his/her work. The ministry may enter into an agreement with a disabled person's interest group under which the interest group will act as an intermediary in finding personal spokesmen and see to giving them information and guidance. The work of a personal spokesman is unpaid; nevertheless, a personal spokesman shall be reimbursed for costs demonstrably incurred in the course of his work in the service of the disabled individual.

All measures taken by a personal spokesman shall be taken in consultation with, and with the approval of, the disabled individual and with his/her interests as the sole guiding principle.

<sup>1)</sup> Act No. 84/2015, Article 26.

#### Article 8

Rights protection officers shall maintain a register of personal spokesmen in their respective regions and monitor their work.

A disabled individual may at any time revoke the appointment of his/her personal spokesman, and the rights protection officer shall help him/her to do this if he/she so requests. The rights protection officer may, with the approval of the disabled individual, revoke the appointment of the personal spokesman, in consultation with the ministry's rights monitoring unit, if he/she considers that the person in question is failing in his duties towards the disabled individual. Furthermore, a personal spokesman may at any time resign from his appointment.

#### Article 9

Under the agreement provided for in paragraph 1 of Article 7, the personal spokesman shall assist the disabled individual, and in particular with the following matters:

1. Defending his rights. The personal spokesman shall assist the disabled individual with preparing an informed decision on matters that concern him/her. The personal spokesman is to assist the disabled individual in situations including when decisions are taken regarding the services which the disabled individual receives or is entitled to. If there is a personal spokesman, then the service provider shall be obliged to summon him/her when substantial changes to the service are about to be made.
2. The disabled individual's personal affairs. The personal spokesman shall be available to help the disabled individual with his personal affairs and support him in preparing to take an informed decision, e.g. regarding treatment by health-care workers, choice of residence, employment, leisure activities, etc. The personal spokesman shall make a comprehensive examination of whether the disabled individual has a good standard of living and make recommendations to the parties concerned, in consultation with the disabled individual, on improvements that could be made.
3. Access to information on financial matters. If the disabled individual pays fees to a joint fund, e.g. a residents' association fund, or towards meeting the costs of housekeeping which he/she shares with others, the personal spokesman shall, under the agreement provided for in paragraph 1 of Article 7, and with the disabled individual's approval, have the right of access

to all information regarding what is done with the money from such funds. For this purpose, the spokesman shall be entitled to attend residents' committee meetings and other such meetings.

4. Help with the disposal of funds to meet day-to-day expenses. The personal spokesman may, under the agreement provided for in paragraph 1 of Article 7, see to the payment of day-to-day expenses for the disabled individual, providing the payments are made with cash drawn from an account specially designated as being for expenses of this type. The personal spokesman may not, on the other hand, enter into financial obligations on behalf of the person he/she assists unless that individual has granted him/her a written authorisation to do so. If a custodian has been appointed for the disabled individual under the Legal Competence Act, then any authorisation issued to the personal spokesman shall not apply to the possessions and finances that are under the supervision of the custodian.

The minister shall issue a regulation<sup>1)</sup> on disabled persons' personal spokesmen containing further provisions on their work, including as regards education and instructions for them, the form of the agreement under paragraph 1 of Article 7 and the reimbursement of expenses under paragraph 2 of Article 7.

<sup>1)</sup> Regulation No. 972/2012.

## [Chapter V

### Measures to reduce compulsion in services to disabled persons.]<sup>1)</sup>

<sup>1)</sup> Act No. 59/2012, Article 2.

#### [Article 10

##### *Prohibition on telemonitoring and the use of compulsion.*

All use of compulsion in dealing with disabled persons shall be prohibited unless exemptions have been granted under Article 12 or in emergency situations covered by Article 13. Telemonitoring of disabled persons' homes shall be prohibited unless exemptions have been granted under Article 12.

The provisions of this Chapter shall apply to all those who provide services to disabled persons in their homes and in their daily life.

Service providers shall be obliged to inform those who work with disabled persons of what constitutes compulsion and the measures that may be taken to avoid having to apply compulsion.]<sup>1)</sup>

<sup>1)</sup> Act No. 59/2012, Article 2; cf. also the Interim provision in the same act.

#### [Article 11

##### *Definitions.*

For the purposes of this Act, 'compulsion' constitutes an action which reduces an individual's right of self-determination and takes place against his/her will, or so restricts his/her right of self-determination that it must be regarded as compulsion even though he/she does not raise any objection to it.

The following are examples of compulsion:

- a. The use of physical force, e.g. in order to prevent a disabled person from injuring himself/herself or other people or causing serious damage to his possessions or those of other persons.
- b. The locking of premises assigned to a disabled individual.
- c. The locking up of a disabled individual or the restriction of his/her freedom of movement by some other means.
- d. The transfer of a disabled individual between places against his/her will.
- e. Restriction of a disabled individual's access to his/her possessions, or their removal against his/her will.
- f. When an individual is forced to do something, for example to take medicinal drugs or to use aids.
- g. The application of force or compulsion in the activities of everyday life.

'Telemonitoring', for the purposes of this Act, means electronic monitoring with the use of a camera or microphone.]<sup>1)</sup>

<sup>1)</sup> Act No. 59/2012, Article 2.

[Article 12  
*Exemptions.*

In special and individual cases, deviations may be permitted from the prohibition stated in paragraph 1 of Article 10 after permission has been granted by the exemptions committee provided for in Article 15, providing that it is demonstrated that the purpose of the compulsion or telemonitoring is as follows:

1. To prevent the disabled individual from causing himself/herself or other persons physical injury or serious property damage. This also applies to preventive measures designed to avoid situations that may result in physical injury or serious property damage.
2. To meet the basic needs of the individual in question, e.g. as regards food, health and hygiene, or to reduce the consequences of a lack of restraint that may result from disability.

When a service provider, director or other person responsible for a service to a disabled individual is obliged to respond to a situation with the result that it may prove necessary to use compulsion on the individual in question, he/she shall consult the specialist team under Article 14.

Telemonitoring shall also meet the conditions of the Personal Data Act.]<sup>1)</sup>

<sup>1)</sup> Act No. 59/2012, Article 2.

[Article 13  
*Emergencies.*

If it is necessary to intervene in a course of events in order to prevent imminent physical injury, serious damage to property or interference with the public interest, compulsion may be applied without the previous taking of a decision as provided for under Article 18. Compulsion shall be discontinued immediately when the danger has been averted or the situation has passed over. Service providers shall record all such instances, stating, amongst other things, the reason why compulsion was applied, what form it took and what interests were at stake. Service providers shall send a description of each instance to the specialist team under Article 14 within a week of when compulsion was applied.]<sup>1)</sup>

<sup>1)</sup> Act No. 59/2012, Article 2.

[Article 14  
*Specialist team.*

The minister shall appoint up to seven individuals for four years at a time to form a specialist team on measures to reduce the use of compulsion. He/she shall appoint the chairman from among their number. The specialist team shall consist of individuals with an expert knowledge of disabled persons' affairs and a knowledge and experience of measures to avoid the use of compulsion. It is envisaged that at least three representatives discuss each case.

The functions of the specialist team shall be as follows:

1. To give service providers and directors advice, amongst other things on what constitutes compulsion and methods of avoiding the use of compulsion.
2. To comment on applications for exemption from the prohibition on the use of compulsion and for exemptions from the prohibition on telemonitoring.
3. To receive notifications of the use of compulsion under Article 13 and reports on the use of compulsion and telemonitoring under exemptions and to maintain a register of instances in which compulsion is applied. The Personal Data Act shall apply regarding procedure and the preservation of the register and materials gathered by telemonitoring. If it is clear, from the registration of instances concerning a particular individual, that the measures for which exemptions have been obtained are not of such a nature as to achieve the intended aim, the team may propose to the exemptions committee that the exemptions be revoked.

Expenses of the team shall be paid by the Treasury. The minister shall issue a regulation<sup>1)</sup> setting further rules on the appointment and working methods of the specialist team.]<sup>2)</sup>

<sup>1)</sup> Regulation No. 970/2012. <sup>2)</sup> Act No. 59/2012, Article 2.

[Article 15

*Committee on exemptions from the prohibition on the use of compulsion.*

The minister shall appoint a three-man exemption committee, and its chairman from among their number, for four years at a time. The committee members shall have expert knowledge of human-rights issues, services to disabled persons and the application of the law in this area. There shall be the same number of alternates, meeting the same qualification requirements as the principal committee members.

The role of the committee shall be to examine applications for exemption from the prohibition on the use of compulsion and for exemption from the prohibition on telemonitoring and to take a decision as to whether exemptions are to be granted.

If an application involves a plan for the substantial and permanent reduction of the freedom of movement of an individual, with the result that he/she will not be able to move freely within his/her home or away from it, the committee must refer the application to the courts. Procedure shall be subject to the provisions of Articles 9-17 of the Legal Competence Act, as appropriate. Permission for the restriction of an individual's freedom of movement shall only be granted if it is demonstrated that there is a danger that the person concerned will cause himself/herself or others substantial physical injury or property damage unless restrictions are imposed on his/her freedom of movement. Appeals may be made to the Supreme Court against decisions taken by judges under this Article. Procedure regarding appeals shall be in accordance with the Code of Civil Procedure, with the deviations set forth in this Act.

Expenses of the committee shall be paid by the Treasury. The minister shall issue a regulation<sup>1)</sup> setting further rules on the committee's working methods.]<sup>2)</sup>

<sup>1)</sup> Regulation No. 971/2012. <sup>2)</sup> Act No. 59/2012, Article 2.

[Article 16

*Applications for exemption from the prohibition on the use of compulsion.*

Service providers shall send the exemption committee as provided for under Article 15 written applications for exemptions from the prohibition on the use of compulsion and exemptions from the prohibition on telemonitoring. In the case of an individual who is personally competent, his/her rights protection officer shall ensure that he/she receives guidance regarding his/her right to choose a personal spokesman.

Applications shall be written on special forms provided by the exemption committee. The following shall be included in applications:

- a. Who is to bear professional responsibility for the use of compulsion.
- b. A description of the circumstances which call for the use of compulsion and arguments supporting its use.
- c. Necessary information about the health of the person concerned.
- d. Whether or not the position of the person concerned has been sought, and if so, what it is.
- e. Confirmation that the position of the person's legal guardian or personal spokesman has been sought. If the person has not chosen a personal spokesman, there shall be evidence that he/she has received guidance regarding his/her right to do so.
- f. Comments by the specialist team provided for in Article 14.
- g. Information about the number of employees, their educational qualifications and training.
- h. How registration and internal monitoring are carried out.

In the case of a child, the informed consent of the child's parent or guardian shall be given for making an application for an exemption from the prohibition on the use of compulsion.]<sup>1)</sup>

<sup>1)</sup> Act No. 59/2012, Article 2.

[Article 17

*Procedure.*

The exemptions committee shall examine applications as soon as possible, and no later than two weeks after they are received. If the committee considers it necessary to gather further materials, this shall be done without delay and a decision shall then be taken as swiftly as possible. The disabled person, his/her legal guardian, personal spokesman or next-of-kin, as appropriate, shall be given an opportunity of expressing his or her opinion to the committee before it takes a decision on the matter.

When dealing with applications, the committee shall give consideration to points including the following, in addition to the conditions stated in Article 12:

1. Whether all other alternatives which do not involve compulsion have been explored.
2. The educational qualifications and experience of the persons who bear professional responsibility for the application of compulsion.
3. Whether the use of compulsion against the disabled person could have a deleterious effect on other individuals who live in the same home.
4. That the compulsion which is the subject of the application is not to exceed what is considered necessary to achieve its aim.]<sup>1)</sup>

<sup>1)</sup> Act No. 59/2012, Article 2.

#### [Article 18

##### *Form and content of decisions.*

If the exemptions committee approves an application for exemption from the prohibition on the use of compulsion on the disabled individual, it shall inform the disabled individual, his/her legal guardian, personal spokesman or closest relatives or person responsible for him/her of this and give them guidance on the right of the person concerned to refer the matter to the courts. The rights protection officer in the region in question shall also be informed of the committee's decision.

The decision shall be backed with reasons, and shall state clearly what sort of measures it covers and the length of time for which it is valid. It shall also state the conditions laid down for the use of compulsion, e.g. as regards how it is to be applied, the demands made of the employees who are to apply it and other matters that the committee considers important. If an exemption is granted, permitting the use of physical force, then the condition shall be set that the employees in question shall have attended a course in the use of physical force.

Permission shall be temporary; it shall never be granted for longer than is necessary, and for a maximum of twelve months at a time.

The committee's decisions are final at the administrative level and may not be referred to a higher authority. Other aspects of procedure, including the re-examination of applications in the light of substantially changed circumstances, shall be subject to the Administrative Procedure Act. A decision by the committee may be referred to a district court judge in the judicial district in which the person concerned is legally domiciled, and the judge shall deliver a ruling on the case within a week of receiving the appeal. Appeals may be lodged with the Supreme Court against rulings by a judge under this Article. Appeals shall be subject to the general rules on civil procedure, with the deviations laid down in this Act. An appeal made under this Article shall not defer the legal effect of the decision against which it is lodged.]<sup>1)</sup>

<sup>1)</sup> Act No. 59/2012, Article 2.

#### [Article 19

##### *Registration.*

Service providers shall maintain a register of all instances in which an individual is subjected to compulsion, whether this is done on the basis of an exemption or in emergency situations under Article 13. The same shall apply to telemonitoring.

The registration shall state how compulsion was applied or how telemonitoring was effected, how long it lasted, who saw to the application and other matters of significance, e.g. whether any injury or property damage resulted from it.

Each month, service providers shall send the specialist team provided for under Article 14 a report on the use of compulsion or telemonitoring on the basis of exemptions. Information on the use of compulsion in emergency situations shall be sent to the specialist team within a week of the occurrence.]<sup>1)</sup>

<sup>1)</sup> Act No. 59/2012, Article 2.

**[Chapter VI]<sup>1)</sup>**

**Miscellaneous provisions.**

<sup>1)</sup> Act No. 59/2012, Article 2.

**[Article 20]<sup>1)</sup>**

*Confidentiality.*

The rights protection officer for disabled persons and personal spokesmen shall observe confidentiality (non-disclosure obligation) regarding all matters of which they become aware in the course of their work and which should remain secret in the interests of the disabled individual. This obligation shall remain in force even after the death of the disabled person and even though the rights protection officer or personal spokesman leaves his position.

<sup>1)</sup> Act No. 59/2012, Article 2.

**[Article 21]<sup>1)</sup>**

*Commencement.*

This Act takes immediate effect.

<sup>1)</sup> Act No. 59/2012, Article 2.

**[Article 22]<sup>1)</sup>**

*Amendments to other legislation.*

...

<sup>1)</sup> Act No. 59/2012, Article 2.

**Interim Provisions.**

**I.**

Without prejudice to the provisions of Article 4 regarding the engagement of the rights protection officer for disabled persons, personal agents appointed on the basis of Article 37 of the Act on the Affairs of Disabled People, No. 59/1992, with subsequent amendments, and the Regulation No. 172/2011, on Disabled Persons' Personal Agents, shall continue to work until the end of their periods of appointment as rights protection officers for disabled persons; when their appointments expire, rights protection officers as provided for under Article 4 shall be engaged.

**II.**

Not later than 1 November 2011, the minister shall submit a bill to the Althingi proposing provisions on measures necessary to reduce the application of compulsion on disabled persons. The minister shall have the bill prepared in collaboration with the [ministry responsible for human rights].<sup>1)</sup>

<sup>1)</sup> Act No. 126/2011, Article 549.

**III.**

Immediately this Act is approved, the minister shall appoint a task force to review the arrangements regarding the protection of the rights of disabled persons with a view to treating the protection of these rights as a human rights issue and not as a welfare issue or a social issue. The task force shall strive to ensure an efficient, effective and progressive method of attending to the protection of disabled persons' rights. In this review, attention shall be given to the United Nations' Convention on the Rights of Persons with Disabilities.

Among the matters to be examined by the task force shall be the possibility of transferring the project to the ministry responsible for human rights issues, the foundation of a national human rights institution to handle the project or conferring on the Icelandic Human Rights Agency responsibility in law for handling the project. In this context, the task force shall give particular attention to the United Nation's Paris Principles.

The task force shall also examine the possibility of pooling specialist skills by transferring all defence and protection of the rights of other groups to the same entity.



The task force shall be composed of representatives of [the ministry and of the ministry responsible for human rights issues],<sup>1)</sup> a range of disabled persons' interest groups, the Association of Local Authorities in Iceland and the Centre for Disability Studies. In addition, assistance shall be sought from experts in human rights issues and specialists in the field of the protection and defence of rights and in disabilities.

The task force shall complete its work not later than 31 December 2011 and submit a report to the minister with proposals for legislative amendments, which the minister shall present to the Althingi.

<sup>1)</sup> Act No. 126/2011, Article 549.

*[This translation is published for information only.  
The original Icelandic text is published in the Law Gazette.  
In case of a possible discrepancy, the original Icelandic text applies.]*