The Icelandic national organization, Throskahjalp National.

The Icelandic national organization, “Thoskahjalp National”, was established in 1976. The organization’s objective is to „fight for the rights and promote the interests of people with intellectual disabilities/challenges, as well as other children and adults with disabilities, and to ensure that their rights are fully comparable to those of other citizens”, as stated in the statutes of the organization.

The organization puts particular emphasis on being a strong advocate for people with intellectual disabilities and for children with disabilities and to empower people with intellectual disabilities to express their opinions and will and to promote and protect their rights and interests.

The operations and policies of Throskahjalp National are based on recognized human rights principles, as underlined in the UN Convention on the Rights of Persons with Disabilities (CRPD).

Just over 20 societies are currently members of the Throskahjalp National: the society of people with intellectual disabilities, parental and supporting clubs, local chapters of Throskahjalp throughout the country, and organizations of professionals who have specialized in working with handicapped people. These societies are active throughout the country and count approximately 6,000 members.

Throskahjalp National has a webpage (www.throskahjalp.is), is on Facebook and publishes the periodical „Throskahjalp“ three times annually.

Ratification of CRDP and the Optional Protocol.

On 30 March 2007, Iceland signed the UN Convention on the Rights of Persons with Disabilities and the Optional Protocol thereto. It has, however, not been ratified.
Throskahjalp National is working vigorously to have Iceland ratify the CRDP and the Optional Protocol as soon as possible, in order to ensure the rights and protection of persons with disabilities better than currently is the case.

Icelandic law is based on the twin concepts of national and international law. Consequently, for international conventions and agreements to become legal instruments in Icelandic courts, they have to be passed as national law. Throskahjalp National considers it important to ensure that CRDP provides persons with disabilities in Iceland the rights and protection which the agreement is supposed to ensure them with certainty, if it is properly ratified and introduced. Therefore it advocates that the Government of Iceland should adopt the agreement as Icelandic law, as was done with the UN Convention on the Rights of the Child in 2013.

**Promotion and protection of human rights of persons with disabilities.**

There is no national human rights institution in Iceland.

The law on persons with disabilities stipulates that local authorities are responsible for service delivery to disabled persons. Local authorities in Iceland number just above 70, serving a national population of around 330 thousand. Many of the local authorities have a very small population and have, consequently, limited capacities to deliver. In response several smaller local authorities band together to form common service arrangements to provide services to persons with disabilities under a joint umbrella. Due to the relatively large number of local authorities and common service arrangements, and due to the leeway given to local authorities, individually and in common arrangements, to design the services, there is a significant risk on inconsistencies in service delivery, that it is insufficient and lacking in equality. Therefore, there is a significant need for a centralized and efficient supervision to ensure that persons with disabilities, wherever they live, receive the public services they are entitled to according to law. The legal responsibility for this rests with the Ministry for Welfare.

Throskahjalp National considers government supervision of the services for persons with disabilities delivered by local authorities is neither sufficient nor efficient enough and that there is a lack of legal instruments for the government to act vis a vis local authorities when needed.

**Equality and non-discrimination.**

In Iceland persons with disabilities suffer discrimination in numerous field, including in housing, employment, education, opportunities for participation in social, cultural and entertainment activities. Furthermore, transfer payments from the government to people who, due to disabilities, are unable to work are so meager that the economy of most persons with disabilities is highly constrained and limits their ability to participate in many of the activities which are considered normal in Icelandic society, e.g. travel etc.
“disability” is not explicitly defined in the equal treatment clause of the Icelandic constitution, nor in public administration legislation and several other laws which include provisions against discrimination. It is the view of Throskahjálp National that it would improve significantly the legal protection of persons with disabilities against discrimination if “discrimination on the basis of disabilities” were to be explicitly stated in the equal protection clauses of the constitution and appropriate laws.

1. **Protection against violence and equal access to justice**

There are strong indications that in Iceland persons with disabilities, and women with disabilities in particular, are subjected to violence in various forms, including sexual violence. The outcome of several recent cases (police investigations, public prosecution decisions and court verdicts) indicate strongly that the justice system does not protect persons with disabilities, e.g. women with intellectual disabilities, as well as other citizens.

Throskahjálp National considers it urgent that Icelandic authorities act swiftly and with determination to ensure that laws, statutes and all legal processes take fully into account the disabilities of involved individuals and ensure that they are not deprived of the important human rights to enjoy protection against violence and have effective access to justice on an equal basis with others.

2. **Laws, statutes and practice concerning pregnancy screenings and abortions.**

In paragraphs 9 and 10 of law no. 25/1975, regarding sexual advice and education and on abortions and sterilization, there are provisions which permit abortions under certain conditions, with associated time limits.

Information provided by the Minister of Health to a question from a member of the Icelandic legislature, Althingi, concerning pregnancy screenings and abortions during the period from 2007 to 2012, shows that 38 cases of Downs syndrome were detected through pregnancy screenings after 12 weeks of pregnancy and all those pregnancies ended with abortion.

Authorities in Iceland have not explained how abortions on the basis of a Downs syndrome fulfill the strong conditions provided in the law. In light of the significance of the procedure Throskahjálp National considers it imperative that the conditions described in the said paragraphs be generally defined to guide practice in pregnancy screenings and abortions, and that reference be made to international commitments which ban discrimination based on disabilities, as well as the United Nationsl Convention on the Rights of Persons with Disabilities and the interpretation of its supervisory authority.¹

Throskahjálp National and the Association on the Downs-syndrome have drawn the attention of the Minister of Health, and other authorities involved and responsible, to this issue with a letter dated 12. February 2016, but have not as of todate received an answer.

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UN Doc CRPD/C/AUT/CO/1
UN Doc CRPD/C/ESP/CO/1
3. **The right to determine one’s place of residence.**

The public services which local authorities provide to persons with disabilities differ between local authorities and common services agreements, as described earlier. There is insufficient supervision by central government concerning equality and consistency in service provision between local authorities and common service agreements.

In many municipalities waiting times for services which persons with disabilities are entitled to and depend on for daily live can be very significant. Consequently, persons with disabilities find it frequently difficult to move domicile from one municipality to another and can, in certain instances, be unable to do so, as they are not able to receive the services they are entitled to from the local authority in the municipality where they want to settle, or have to wait a long time before receiving the needed services.

This practice and the insufficient supervision of local authorities, provided by central government, and the absence of regulations which ensure equality and consistency between local authorities, seriously undermines the rights of persons with disabilities in Iceland to determine their place of residence.

**Participation in political and public life.**

*Throskahjalp National* has drawn the attention of Icelandic authorities to their obligation to guarantee the free expression of the will of persons with intellectual disability as electors and to this end, where necessary, at their request, allow assistance in voting by a person of their own choice as provided for e.g. in Article 29 of CRPD. As of today, this has not been guaranteed properly in Icelandic legislation and administration.