

**Vammaisfoorumi ry
Handikappforum rf
Finnish Disability Forum**

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An NGO Contribution to the Universal Periodic Review Mechanism

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In the context of Universal Periodic Review Mechanism and the case of Finland we wish to highlight some crucial aspects in the realisation of human rights of persons with disabilities in Finland.

The Finnish Disability Forum is member of the European Disability Forum. Founded in 1999, the Finnish Disability Forum is a cross disability umbrella organisation to represent Finnish disability NGOs nationally, in European Union and internationally, we currently have 28 member organisations which themselves have over 320 000 individual members (see Annex 1). This paper was prepared in consultation with advocacy network of experts from member organisations and in collaboration with VIKE – The Center for Human Rights of Persons with Disabilities.

1. Ratification of the CRPD

The Finnish Disability Forum urges the government of Finland to ratify CRPD (Convention on the Rights of Persons with Disabilities, (A/RES/61/106) in the nearest possible future. However, we do take note of the fact that some crucial changes to the domestic legislation concerning persons with disabilities have to be made prior to the ratification. The Finnish Disability Forum notes with satisfaction in the government programme of the government of Prime Minister Jyrki Katainen (June 22, 2011) the commitment to ratify the CRPD and its optional protocol before the end of the ongoing governmental period. It is vital that this commitment be followed through.

As to the necessary changes to current national legislation, Finnish Disability Forum together with VIKE The Center for Human Rights of Persons with Disabilities (Finland) have submitted a paper to the Ministry for Foreign Affairs of Finland (dated 25 September 2007) in which were described shortcomings of the domestic legislation of Finland in relation to CRPD. Changes are being prepared, in particular in relation to client self-determination and its limitations in social welfare and health care; and some have already been introduced to facilitate the changing of municipality of residence for persons with disabilities in need of social welfare or disability services. Notwithstanding, there are a number of areas remaining where the realisation of rights in practice is only an aspiration: equal access to tertiary and vocational training is nominally assured in the legislation, yet for the right to education to be real and effective in practice, the necessary support measures must be provided by education institutions or municipalities responsible for services and assistance for persons with disabilities. In this provision, there are local variations and delays. For example, only one of every thousand students in universities and polytechnics is a student with disability. There are fewer students with disabilities in higher education than their proportion of the age cohort. This reflects the barriers that remain despite the many projects that aim to further access of persons with disabilities to higher education.

The Finnish Disability Forum, would like to point out that the general obligations of CRPD would also need to be fully taken into consideration, including for example the realisation of non-discrimination and equality. While ratifying CRPD a decision will have to be made on how strongly these general obligations will be taken into consideration. This is particularly true in relation to the scope of equality and non-discrimination provisions; these have far reaching effects on the future of the legislation and consequently on the situation of persons with disabilities. The ratification of CRPD offers an opportunity to further improve and strengthen not only the legislative framework of non-discrimination and equality on the grounds of disability but also to make rights a reality through effective implementation of active policies and thus adopt a more proactive human rights based approach to disability. The choice to fully utilise the potential of the CRPD for proactive promotion of full participation in society and full equality of persons with disabilities is a necessary one for a States Party that is committed to promotion of human rights.

One element of an effective implementation is the full participation and active involvement of disability NGOs in the promotion, protection and monitoring of the human rights treaty framework. It is essential that the new monitoring framework, including the focal point and co-ordination

mechanisms, and independent mechanisms do include full and effective representation of persons with disability and their representative organisations, in accordance with CRPD 33 (2) and (3).

Deficiencies in the Non-Discrimination Legislation

The domestic legislation concerning equality is currently spread over a number of provisions, which leads it to be somewhat incoherent in nature and very difficult to grasp for the citizens. The combined implementation of two pieces of European Union legislation, ie the Framework Employment Directive 78/2000/EC and the Race Directive 43/2000/EC by the drafting of the Non-Discrimination Act (21/2004) led to an unequal situation: the scope of application and legal remedies are much more comprehensive in case of discrimination based on ethnic discrimination than that of other grounds. This state of affairs can not be considered as being consistent with the principle of equality and the norms regulating it. The Finnish Non-Discrimination Act is discriminating in itself, as it provides different treatment in terms of different grounds of discrimination – without acceptable justification for this distinction.

While the Non-Discrimination Act does acknowledge the denial of reasonable accommodation as a form of indirect discrimination, the positive potential of this provision is in the main lost due to shortcomings in the way this Act is to be monitored. Monitoring mechanisms are very weak and their personnel do not have relevant expertise in disability issues. As regards cases of discrimination concerning, inter alia, providing services and health care, disability cases fall outside the scope of application. In addition, the article on compensation (art. 9) is written in such an obscure manner that has given rise to conflicting interpretations among legal scholars.

When persons with disabilities face discrimination on the ground of their disability or even on other prohibited grounds, they have no access to effective legal safeguards. The possibility of taking a case to court as a civil lawsuit remains illusory for most persons with disability – considering, for example, the risk of having to cover costs of both parties in case of loss, and the overall imbalance of the parties. In other words, it seems that even if Finland has some legislation on non-discrimination, it is not enough to protect persons with disabilities from discrimination even in those cases where the act of discrimination is uncontestable.

To address the current gaps in protection and remedies against discrimination on the ground of disability, the Finnish Disability Forum considers it important that the deficiencies within the Non-

Discrimination Act be corrected. A working group under Ministry of Employment and the Economy is currently drafting a new proposal, but it is vital that the inherent flaws of the current Act be remedied properly. As of now, the situation remains most unsatisfactory, with no effective monitoring, sanctions or remedies available to victims of disability discrimination in areas other than employment and education. As regards employment and education, there is very little disability awareness among authorities and employers and the monitoring of employment discrimination is centered on issues other than disability, especially ethnic minorities and human trafficking.

There is also need for establishment of an independent body whose mandate would also include capacity to intervene to cases of discrimination of persons with disabilities in all different spheres of life. The body's mandate should also include counseling, supporting persons in legal proceedings, awareness-raising, research, implementation of non-discrimination legislation and also mandate to mediate. We welcome the establishment of a national human rights institute, which is expected to become operational in the course of 2012. We remain concerned of the very limited human and operational resources awarded to the institute – particularly in view of its mandate. This is why we remain convinced that the disability specific expertise within such a generalized body must be strengthened.

3. Lack of Inspection in Institutional Settings and Use of Coercive Measures

After a number of incidents of manslaughter and maltreatment in institutions an extensive discussion has again taken place in the media over the circumstances on the institutional setting in which persons with disabilities reside. The cases that resulted in vulnerable residents dying in institutions have further accelerated the discussion. In consequence, the shortcomings of the legislation, in particular regarding the inspection systems and the practises relating to the enforcement of such legislation.

The general bodies that execute judicial monitoring of institutions do not have resources or the expertise to monitor institutions in which persons with disabilities reside. In Finland, there is currently no special body to monitor these institutions. Especially the situation of persons with intellectual disabilities is highly fragile because of the magnitude of institutional living settings in Finland.

Also the legal monitoring of the use of measures against the will of the individual, such as use of isolation or constraints for disciplinary purposes in residential institutions, remains weak in its powers and resources. The culture of using such disciplinary or constraining measures is very secretive in character; this leads to no confidence on the legitimacy of the use of coercive measures. Many disability organisations receive constantly information on cases where misuse of such measures is to be suspected to have taken place. The legislation on the use of coercive measures is quite old, especially in the case of persons with intellectual disabilities (1977); instead of restricting or minimising the use of such measures, this legislation is mandating their use. The legislation also varies – there are different pieces of legislation concerning different disability groups with variable measures.

In this context, the Finnish Disability Forum would like to note a positive development: currently a ministerial working group is drafting proposal to modernise the provisions concerning involuntary measures in social services and health care. The working group is expected to finalise a proposal for a government Bill by end of 2012.

4. Right to Choose Place of Residence

The Municipality of Residence Act (201/1994) has been changed to improve the situation of persons with disabilities and give them equal rights to change their place of residence. In practice, however, the changes only obligate municipalities to draft a service plan for the person planning to move; this service plan is non-binding on the municipality and does not create justiciable decision for the person. In practice, persons with disabilities are obliged to live where the local government is willing to provide the necessary services. For example, a person with a disability may be pressured to live in an institution even in case it would be possible for her to live in a place of her own choosing, with the appropriate personal assistance, and this would be her own preference. In situations such as these, the personal preferences of the person may be set aside.

5. Assistance of the Persons with Disabilities in greater need of support

The Services and Assistance for the Disabled Act (380/1987) was significantly amended in 2008. The amendments came into effect from 1 September 2009, entitling personal assistance to persons with severe disability, persons who due to a long-term progressive disability or illness, necessarily and continuously need assistance of another person for activities of daily life. This need for

assistance shall not be primarily due to illnesses or limitations in functioning that are related to ageing. A second requirement is that the person must be able to define the contents and the delivery method of the personal assistance. In case the person needs assistance for care, medical treatment or for behaviour monitoring, these needs must be met with services other than personal assistance.

Personal assistance shall be organised for purposes of activities of daily life, of work and study to the extent that the person with severe disability necessarily needs. For hobby activities, participation in community and in social life, the assistance is limited to a minimum of 10 hrs per month, from beginning of 2011, the minimum level will be 30 hrs per month.

There are also procedural reforms meant to strengthen the access to services: when the client contacts the services, his or her service needs must be examined promptly. The examination must begin within 7 business days from the client's first contact. A services plan which outlines the services provided for the client must be drawn up without undue delay, and decisions regarding award of services have to be made within 3 months of when application was first submitted. It is important to note that municipalities can no longer refuse personal assistance to those persons who meet criteria set down in the act.

In practice, however, the implementation still remains uneven across municipalities. The financial and budgetary pressures on municipal social services have led to deficient implementation in some places. Particularly, persons with developmental disabilities have been removed from the personal assistance system on the grounds of their presumed inability to define the contents and the delivery method of personal assistance.

6. Inaccessible Housing and Built Environment

The legislation concerning renovation of old buildings to be accessible is rather good in Finland but the practice fails in enhancing the legislation in an effective way. The reality shows that people can not live in a normal living environment because the supply of accessible apartments is very limited.

Also, the process of deinstitutionalisation that is promoted via Government Programme of Housing for Persons with Intellectual Disabilities. The building of community housing is marred by the Not In My Backyard or NIMBY phenomenon, recently mediatized in Turku, where residents waged a campaign against a planned new group home for disabled persons, citing the loss of their property value due to proximity of persons with intellectual disabilities.

7. VAMPO – Finland’s Disability Policy Programme (2010-2015)

A specific Government Disability Policy Programme outlining the most important measures to be undertaken in the field of disability policy was published on 26 August, 2010. The work started in September 2008 and was completed in March 2010. The most important documents on which the work is based are the first Government Report on Disability Policy (2006) and the United Nations Convention on the Rights of Persons with Disabilities and the Optional Protocol. Finland signed both the Convention and the Optional Protocol in 2007. The strategic work areas include:

- Independent living (housing, movement, communication and access to information, use of services)
- Social action, involvement, inclusion (civil rights, legal capacity, measures against a person’s own will)
- Building
- Transport
- Education (studies, life-long learning)
- Work (finding employment, doing work, reasonable income)
- Health
- Rehabilitation, social protection
- Safety, integrity
- Culture (leisure, physical activity, art)
- Other (international cooperation, statistics and information collection)

Under the 14 content areas, 122 measures are outlined, developing all the relevant policy sectors from the perspective of the rights, freedoms and equal opportunities of persons with disabilities. With regard to each measure, the following has been examined: administrative sector responsible for implementation, timetables, financial needs, obligations an indicator by which the implementation of the measure is followed.

Sources: National Council on Disability in Finland, VANE, www.vane.to/vampo_yleis_eng.html
 Ministry of Social Affairs and Health www.stm.fi.

It should be noted that a majority of the measures should need to be implemented without any additional resources. But it can be highlighted as a recent major policy document. Its actual implementation and effectiveness can only be evaluated over time. At present, we can only state that in the process of preparation of Disability Policy Programme, disability NGOs were actively involved and participated fully.

8. Need for disability specific data and statistics

The Finnish Disability Forum would wish to highlight the need for a more extensive and systematic data collection and research on the situation of persons with disabilities in Finland, in particular their socio-economic status and living conditions. The data collection should be systematic in nature, and disaggregated on the basis of gender; there is very little gender specific information on the status of disabled women and girl children in Finland. The need to have baseline information and an extensive overview of the situation of all persons with disabilities, young and old, men and women, also persons with disabilities from minority backgrounds, underlines the urgency for disability research.

As a positive development, we would like to draw attention to the successful collection of funds among disability NGOs and service providers to donate a chair in disability studies to the University of Helsinki. The new chair – yet to be nominated - will provide for a fixed period of 4 years, a new resource for furthering of disability studies. We would emphasise that the maintenance of such resources should not be dependent on civil society alone.

Collection of data and statistics on disability-specific issues is the duty of government, this duty should not be left unfulfilled on the basis of financial constraints. There are several organisations, including Kela – Social Insurance Institution and the National Institute on Health and Welfare, whose mandates should be strengthened in this area. As a general remark, we would underline the very limited resources for disability related issues within the ministries and the National Institute on Health and Welfare. We are able and willing to assist the very limited number of disability experts in the ministries, such a dialogue and exchange of information is essential for full participation in matters concerning us. However, more experts are needed, to cover the range of substantive issues covered by the CRPD.

In conclusion, it could be said that the positive changes are undermined by late or unequal implementation of those positive measures. On the policy document level, we have a brand new Disability Policy Programme. We have the promise of a ratification of CRPD, accompanied by legislative changes to remove discriminatory practices. However, steps in the positive directions are small, and we witness a re-emergence of negative attitudes which highlights the need for further awareness-raising campaigns, particularly in support of victims of disability discrimination.

9. Recommendations

- 1) Ratification and effective implementation of CRPD with full participation and active involvement of representative disability NGOs in the promotion, protection and monitoring of the human rights treaty framework.
- 2) The new monitoring framework, including the focal point and co-ordination mechanisms, and independent mechanisms need to include full and effective representation of persons with disability and their representative organisations, in accordance with CRPD 33 (2) and (3).
- 3) The need for a more extensive and systematic data collection and research on the situation of persons with disabilities in Finland, in particular their socio-economic status and living conditions. The data collection should be systematic in nature, and disaggregated on the basis of gender.
- 4) The need to further improve and strengthen the legislative framework of non-discrimination and equality on the grounds of disability. To make rights a reality through effective implementation of active policies, to adopt a more proactive human rights based approach to disability.
- 5) The mainstreaming of disability perspective in other human rights policy areas needs to be continued, and strengthened in line with the positive example in the area of the development policy of Finland, where disability NGOs play an active role.
- 6) The need to further improve human resources in the ministries and other public bodies, to strengthen disability related expertise across the administration.

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Annex 1

Member organisations of Finnish Disability Forum (as of 14.11. 2011)

Aivoliitto ry	Finnish Stroke Association
Aivovammaliitto ry	no official English translation, Association of persons with brain injury
Autismi- ja Aspergerliitto ry	The Finnish Association for Autism and Asperger's syndrome
Epilepsialiitto ry	The Finnish Epilepsy Association
Finlands Svenska Handikappförbund rf	no eng Association of Swedish Speaking Persons with Physical Disabilities
Förbundet De Utvecklingstördas Väl FDUV rf	Association for the care of persons with intellectual disability
Förbundet Finlands Svenska Synskadade	The Federation of Swedish Speaking Visually Impaired in Finland
Hengitysliitto Heli ry	Pulmonary Association Heli
Heta-liitto ry	no transl, Association of employers of personal assistants
Invalidiliitto ry	Finnish Association of People with Physical Disabilities
Kehitysvammaisten Tukiliitto ry	The Finnish Association for Persons with Intellectual Disabilities
Kehitysvammaliitto ry	The Finnish Association on Intellectual and Developmental Disabilities (FAIDD)
Kuuloliitto ry	The Finnish Federation of the Hard of Hearing
Kuurojen Liitto ry	The Finnish Association of the Deaf
Kynnys ry	The Threshold Association
Me Itse ry	no transl association of self advocates, people with intellectual disabilities
Lihastautiliitto ry	The Finnish Association of Muscular Dystrophy
Mielenterveyden keskusliitto ry	Finnish Central Association for Mental Health
Näkövammaisten Keskusliitto ry	Finnish Federation of the Visually Impaired
Psoriasisliitto ry	The Finnish Psoriasis Association
Selkäydinvammaiset Akson ry	Finnish Spinal Cord Injured Association – Akson
Sotainvalidien Veljesliitto ry	Disabled War Veterans of Finland Association
Suomen CP-liitto ry	Finnish Cerebral Palsy Association
Suomen Diabetesliitto ry	The Finnish Diabetes Association
Suomen Kuurosokeat ry	The Finnish Deafblind Association
Suomen MS-liitto ry	Finnish Multiple Sclerosis Association
Suomen Polioliitto ry	Finnish Polio Association
Suomen Reumaliitto ry	Finnish Rheumatism Association