



Umsögn Landssamtakanna Þroskahjálpar um frumvarp til laga um dánaraðstoð, 771. mál

25. mars 2024

Landssamtökin Þroskahjálpar vinna að réttinda- og hagsmunamálum fatlaðs fólks, með sérstaka áherslu á fólk með þroskahömlun og/eða skyldar fatlanir og einhverft fólk og fötluð börn og ungmenni. Samtökin byggja stefnu sína á samningi Sameinuðu þjóðanna um réttindi fatlaðs fólks, barnasáttmála SP og öðrum fjölþjóðlegum mannréttindasamningum, sem og heimsmarkmiðum SP, sem hafa það meginmarkmið að **skilja engan eftir**.

Íslenska ríkið fullgilti samning SP um réttindi fatlaðs fólks árið 2016 og skuldbatt sig þar með til að framfylgja öllum ákvæðum hans. Í stjórnarsáttmála ríkisstjórnarinnar segir að samningurinn verði lögfestur og nú er í gangi af hálfu ríkisins sérstök landsáætlun um innleiðingu hans. Samninginn má nálgast á hlekk að neðan.

<https://www.stjornarradid.is/efst-a-baugi/frettir/stok-frett/2021/07/07/Ny-thyding-a-samningi-Sameinudu-thjodanna-um-rettindi-fatlads-folks/>

Í samningnum eru ýmis ákvæði sem geta haft verulega þýðingu m.t.t. þess máls sem hér er til umfjöllunar, m.a. í **5. gr.** samningsins sem hefur yfirskriftina **Jafnrétti og bann við mismunun**, í **10. gr.** sem hefur yfirskriftina **Réttur til lífs**, í **12. gr.** sem hefur yfirskriftina **Jöfn viðurkenning fyrir lögum**, í **17. gr.** sem hefur yfirskriftina **Verndun friðhelgi einstaklingsins**, í **25. gr.** sem hefur yfirskriftina **Heilbrigði** og í **28. gr.** sem hefur yfirskriftina **Viðunandi líf skjör og félagsleg vernd**.

Nefnda- og greiningarsvið Alþingis sendi Landssamtökunum Þroskahjálpar frumvarpið til umsagnar með tölvupósti 12. mars sl. Í tölvupóstinum segir: *Frestur til að senda inn umsögn er til og með 26. mars nk.*

Að mati samtakanna er það augljóslega allt of skammur frestur til að fjalla um svo flókið og margþætt mál þar sem reynir á mörg og margvísleg siðferðileg og lagaleg álitæfni. Samtökin hafa því ekki haft nauðsynlegt ráðrúm til að ræða frumvarpið nægilega innan sinna vébanda og geta því ekki að svo stöddu tekið afstöðu til þess en vilja á þessu stigi koma á framfæri við velferðarnefnd og Alþingi umfjöllun **óháðs sérfræðings Sameinuðu þjóðanna um réttindi fatlaðs fólks** (UN Special Rapporteur on the rights of persons with disabilities) um dánaraðstoð í skýrslu frá 17. desember 2019, þar sem hann fjallar um ýmislegt varðandi lækisfræði og vísindi og framkvæmd á því sviði m.t.t. fatlaðs fólks (A/73/161: Report of the Special Rapporteur on the rights of persons with disabilities). Skýrsluna má nálgast á hlekk að neðan.

<https://www.ohchr.org/en/documents/thematic-reports/a73161-report-special-rapporteur-rights-persons-disabilities>

Hér á eftir fara orðrétt nokkrir kaflar úr skýrslunni, þar sem fjallað er um dánaraðstoð.

V. Contemporary challenges

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35. *The disability community has expressed significant concerns about the potential dangers of withdrawal and withholding of life-sustaining treatment on the basis of disability. While withdrawal and withholding of treatment can be ethical and medically appropriate in some circumstances, it has been reported that physicians may exert pressure on critically ill patients and their families to withhold or withdraw life-sustaining treatment based on the belief that further treatment would be futile, non-beneficial or potentially inappropriate, particularly for patients with severe impairments. That subjective assessment, based on the physician's opinion and values, includes an assumption on the resulting quality of life of the individual and thus involves a risk that it is influenced by ableist views of living with a disability. Similarly, cost-effectiveness considerations may also result in the denial of life-sustaining treatments to some persons with disabilities.*

36. *Assisted dying, whether through euthanasia or assisted suicide, is a contentious issue within the disability community. Euthanasia generally entails the consented administration of a lethal substance by a third person, usually a physician, to end a person's life; assisted suicide refers to the prescription of a lethal substance for self-administration by the individual. To date, assisted dying is legal in only eight countries, but many others are considering its implementation. The practice and requirements for assisted dying vary across jurisdictions; in some, euthanasia performed by physicians is predominant, whereas in others only assisted suicide is permitted. Additionally, while in some jurisdictions assisted dying is restricted to adults who are terminally ill, some countries offer assisted dying for anyone with a medical condition who experiences severe physical or mental pain and suffering. Countries where assisted dying is performed by physicians and that have broad access criteria have higher percentages of assisted dying and have experienced a significant expansion of the practice over the last decade.*

37. *From a disability rights perspective, there is a grave concern that legalizing euthanasia and assisted suicide could put at risk the lives of persons with disabilities. If assisted dying is made available for all persons with a health condition or impairment, regardless of whether they are terminally ill or not, a social assumption might follow that it is better to be dead than to live with a disability. Therefore, a first concern is that with a newly acquired impairment may opt for assisted dying based on prejudices, fears and low expectations of living with a disability, before even having the chance of coming to terms with and adapting to their new disability status. Second, persons with disabilities may decide to end their lives because of social factors, including loneliness, social isolation and lack of access to quality support services. A third problem is that persons with disabilities, particularly older persons with disabilities, may be vulnerable to explicit or implicit pressures arising from their context, including expectations from family members, financial pressures, cultural messages and even coercion.*

38. *Generally, when life-ending interventions are normalized outside the end stage of terminal illness, persons with disabilities and older people may increasingly feel the need to end their lives. For example, the available data from two countries show an increase in the demand for*

euthanasia among people who are not terminally ill, particularly persons with psychosocial disabilities and dementia. Nevertheless, many disability rights advocates also oppose assisted dying in terminally ill contexts, as they fear it will put at risk persons with new or progressive disabilities or diseases, who may be mistakenly diagnosed as terminally ill but who have many years of life ahead of them.

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D. Protecting the right to life

68. States must protect the rights of persons with disabilities on an equal basis with others. They must adopt legislation to expressly prohibit discrimination on the basis of disability in decisions to withhold or withdraw life-sustaining treatment. Those decisions must respect the rights, will and preferences of individuals, including advance directives. States must also consider adopting legislation banning discrimination on the basis of disability in organ transplantation. Persons with disabilities must receive equal priority for organ transplants. Expedited complaint procedures and robust remedies are needed to protect the right to life of persons with disabilities adequately in both situations.

69. States considering legalizing any form of assisted dying should conduct extensive discussions with the active participation of organizations representing persons with disabilities. In such debates, States should pay particular attention to the social factors that may affect the decisions of persons with disabilities in relation to assisted dying, including ableism, social stigma and discrimination, societal views on the quality of life of persons with disabilities and the availability of community support and services, social protection programmes and palliative care. Assisted dying must not be seen as a cost-effective alternative to providing personal assistance and disability services for persons with disabilities, in particular those with high support needs.

70. If assisted dying is to be permitted, it must be accompanied by strong measures to protect the right to life of persons with disabilities. First, access to assisted dying should be restricted to those who are at the end of life; having an impairment should never be a reason for assisted dying to be permitted. Second, the free and informed consent of persons with disabilities must be secured on all matters relating to assisted dying and all forms of pressure and undue influence prevented. Third, access to appropriate palliative care, rightsbased support (see A/HRC/34/58), home care and other social measures must be guaranteed; decisions about assisted death should not be made because life has been made unbearable through lack of choices and control. Fourth, accurate information about the prognosis and availability of peer-support counselling must be provided. Fifth, accountability regulations must be established requiring collection and reporting of detailed information about each request and intervention for assistance in dying.

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E. Participation in decision-making

71. States must closely consult with and actively involve persons with disabilities and their representative organizations, including children and women with disabilities, in the adoption, implementation and evaluation of legislation and policies about medical and scientific

research and experimentation, prenatal screening, assisted dying and other issues directly or indirectly related to the value of the lives of persons with disabilities. Girls, boys and adolescents with disabilities, even the youngest, are the experts on their own lives and thus also have the right to participate in decision-making and to be provided with disability and age-appropriate support for that purpose (see A/72/133).

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VIII. Conclusions and recommendations

73. The hegemony of ableism in society has perpetuated the idea that living with a disability is a life not worth living. There is a deep-rooted belief, carved with fear, stigma and ignorance, that persons with disabilities cannot enjoy a fulfilling life, that their lives are incomplete and unfortunate, and that they cannot attain a good quality of life. Such ableist ways of thinking, reinforced by the medical model, have privileged prevention and cure over all other responses to disability, leaving persons with disabilities with limited opportunities to be included and participate in society. While the eugenic programmes of the late nineteenth and early twentieth centuries have disappeared, eugenic aspirations persist in current debates related to medical and scientific practice concerning disability, such as prevention, normalizing therapies and assisted dying. Notwithstanding all the progress achieved over recent decades concerning the rights of persons with disabilities, embracing disability as a positive aspect of humanity remains the final frontier to be conquered.

74. Life with a disability is a life worth living equal to others. Every person has a unique set of unrepeatable characteristics and experiences that make them irreplaceable and valuable. The lives of persons with disabilities are human lives and, consequently, endowed with inherent dignity. Persons with disabilities can live fulfilling lives and enjoy what gives life meaning. They share the same aspirations as everyone else, such as making friends, getting a job, living on their own, starting a family or accomplishing their dreams. Persons with disabilities bring talent, diversity and richness to their communities. While they may face more barriers in achieving their aspirations, their endeavours and accomplishments contribute to building more inclusive and diverse societies for the benefit of all.

75. Given the cultural and societal challenges posed by ableism, neither awareness-raising programmes nor the generalization of anti-discrimination measures will alone suffice. What is needed is a cultural transformation of the way society relates to the difference of disability. That is a commitment to the recognition of persons with disabilities as equals on all terms, with the same rights and opportunities as everyone else in society. It is thus vital to reduce the distance between society's views of disability and the narratives of those living with a disability. The devaluation of the lives of persons with disabilities comes partly from a historic inability to listen to what persons with disabilities have to say about themselves.

76. The Special Rapporteur makes the following recommendations to States, with the aim of assisting them in developing and implementing reforms that will lead to the recognition and acceptance of disability as part of human diversity: A/HRC/43/41 18

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(f) Where assisted dying is permitted, implement strong measures to protect the right to life of persons with disabilities on an equal basis with others;

Landssamtökin Þroskahjálp lýsa miklum vilja til virks og náins samstarfs og samráðs við hlutaðeigandi stjórnvöld og Alþingi um þau mál sem hér eru til umfjöllunar og vísa í því sambandi til til 3. mgr. 4. gr. samnings SP um réttindi fatlaðs fólks, sem hefur yfirskriftina **Almennar skuldbindingar:**

Þegar aðildarríkin undirbúa löggjöf sína og stefnu samningi þessum til framkvæmdar og vinna að því að taka ákvarðanir um málefni sem varða fatlað fólk skulu þau hafa náð samráð við fatlað fólk og tryggja virka þátttöku þess, einnig fatlaðra barna, með milligöngu samtaka sem koma fram fyrir þess hönd.

Virðingarfyllt.

Unnur Helga Óttarsdóttir, formaður Þroskahjálpar

Árni Múli Jónasson, framkvæmdastjóri Þroskahjálpar