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NETHERLANDS

The Center for Family and Human Rights (C-Fam) is a nongovernmental organization which was founded in 1997 and has held Special Consultative Status with the UN Economic and Social Council since 2014. We are headquartered in New York and Washington, D.C. and are a nonprofit, nonpartisan research and advocacy organization that is dedicated to reestablishing a proper understanding of international law, protecting national sovereignty and the dignity of the human person.

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INTRODUCTION

1. This report focuses on the protection of the right to life and the rights of persons affected by the Netherlands' euthanasia policies and the practice of eugenic prenatal screening.
2. The practice of euthanasia and assisted suicide in Netherlands violates the right to life protected by Article 6 of the International Covenant on Civil and Political Rights (ICCPR), Article 6 of the Convention on the Rights of the Child, both of which have been ratified by the Netherlands, and Article 3 of the Universal Declaration of Human Rights.
3. In addition, the Netherlands' eugenic prenatal screening practices violate the right to life and the rights of persons with disabilities, in particular unborn children diagnosed with Trisomy 21, otherwise known as Down syndrome.

EUTHANASIA AND THE RIGHT TO LIFE

Background

4. In 2002, the Netherlands was the first European state to legalize euthanasia. The Termination of Life on Request and Assisted Suicide (Reviews Procedures) Act 2002 (the Termination of Life Act) regulates the practice of euthanasia and assisted suicide in the Netherlands. Under the Termination of Life Act, physicians may euthanize or assist in the suicide of patients if certain criteria are met. For example, patients must experience "unbearable suffering," and they must make a voluntary request for euthanasia. Patients need not suffer from a terminal illness to make a euthanasia request.
5. Euthanasia is permitted for children ages 12-16 provided they have obtained permission from their parents. Adolescents ages 16-19 may be euthanized provided that their parents or guardian are involved in the making the decision.
6. Persons aged 16 or older who lack capacity to express their will can be euthanized if they have made a written request to be euthanized prior to losing their capacity.
7. In addition, since 2005, a protocol known as the "Groningen Protocol" lists the necessary conditions and steps to be followed in the context of end-of-life decisions for young children, especially newborns. In cases where the children cannot understand or speak for themselves, the doctor, with both parents' consent, could choose euthanasia.[1]
8. In 2020, the Dutch government agreed on plans to make euthanasia legal for terminally ill children under the age of 12. According to the Dutch Health Minister, the current law would not need to be amended. Rather, doctors would be exempted from prosecution for carrying out an approved euthanasia on a child.[2]
9. Many organizations continue to pressure the Netherlands to expand its criteria for euthanasia and physician assisted suicide. For example, in 2016 the Dutch government considered a new law that would allow assisted suicide for the elderly who were "tired of living." Although many medical professionals and other experts have spoken out against the bill, both the Minister of Health and the Minister of Justice continue to push for its passing.[3] Dutch MP Pia

Dijkstra proposed a similar law in 2020, which, if passed, would allow a healthy over-75-year-old who is tired of life to be legally euthanized.[4] To date the law has not passed.

10. Although the Termination of Life Act has not legally changed since its enactment, broader interpretations are increasingly common. In practice, the interpretation of the law has expanded, making euthanasia more accessible. For example, as many as 1700 individuals were inappropriately sedated, causing their death. A 2017 study revealed that deaths by "deep and continuous sedation until death" had risen by 8.2% in 2005 to 18% in 2015.[5]

11. In addition, although the Termination of Life Act strictly states that a patient's request for euthanasia must be voluntary and well-considered, individuals with psychiatric disorders or dementia are euthanized even though competency is difficult to determine. In 2009, the Regional Euthanasia Review Committee reported 12 cases of euthanasia for neurological diseases. In 2016, 201 euthanasia cases were reported for psychiatric illnesses (60) and dementia (141). In 2019, the number rose to 230, with 162 patients with dementia and 68 patients suffering with psychiatric disorders euthanized.[6] In some of these cases, such as cases involving a patient with advanced dementia, the patient has made no explicit request for death; rather, the physician is relying upon an advanced medical directive executed before the diagnosis.

12. In 2018, the Euthanasia Code was updated to allow for sedation in advance of administering prior to carrying out the euthanasia procedure after a doctor was prosecuted for sedating a demented patient before euthanizing her patient. She was later cleared and exonerated with the Euthanasia Review Committee finding that, "it is not necessary for the doctor to agree with the patient the time or manner in which euthanasia will be given."[7]

13. Access to euthanasia is also increasing with the advent of mobile euthanasia teams and the opening of the "Euthanasia Expertise Center" (EEC). According to the Regional Euthanasia Review Committee, doctors at EEC clinics performed approximately 400 cases of euthanasia in 2016, compared with 107 in 2013.[8]

14. Further exacerbating the potential for abuse of euthanasia is the relaxed attitude of the Regional Euthanasia Review Committees and permissive judicial decisions. For example, in 2014, the Regional Review Committee accused the EEC clinics of irregularities in their files. In 2015, two cases of euthanasia were deemed non-compliant with legal requirements by the Regional Review Committee. Despite the EEC's failure to comply with the law, no criminal charges were filed.[9]

Cases reported by the Netherlands Euthanasia Committee

15. In 2019, a man in his sixties suffering from serious alcoholism, depression, and narcissistic and antisocial personality disorders was euthanized because both the patient's physician and the independent physician concluded that the patient was "decisionally competent" in relation to his request for euthanasia, and that the patient's suffering was without prospect of improvement and that there were no reasonable treatment options left.[10]

16. In 2019, a man in his eighties was diagnosed with Alzheimer's disease two years before his death. A year before the patient's death, his general practitioner discussed euthanasia with him on several occasions. At that time, the patient's request for euthanasia pursuant to his advanced directive was not immediately relevant. During the discussions about euthanasia,

the patient no longer had any awareness of his Alzheimer's diagnosis nor was there a request for euthanasia. However, as the patient's condition deteriorated, he soon became unable to live at home and required 24-hour care at a nursing facility. He was sedated and dependent on others for his everyday needs. Pursuant to his advance directive, the patient requested to be euthanized if dementia causes humiliation in the form of incontinence and loss of personal dignity without prospect of improvement. The patient's general practitioner did not wish to perform the euthanasia procedure because he considered the request too complex and referred the patient to the EEC clinic. The EEC physician found that the patient's condition was unbearable, and with the support of the patient's friends and family granted the euthanasia request. The patient was taken home on the day the euthanasia was performed. He allowed the IV cannula to be inserted, and when the physician informed him that he was about to carry out the euthanasia procedure, the patient did not respond.[11]

17. In another case, a man in his seventies who suffered from cognitive problems was euthanized pursuant to an advanced directive. The procedure was carried out at the nursing home. The EEC nurse explained to the patient that they were going to give him substances that would end his life and he would first be given medication to calm him. He ingested the medication. After resting for some time, the patient wanted to get up at which point they allowed him to walk around the room. He laid down in his bed again but was agitated. Therefore, they administered a sedative and morphine. Shortly after, the patient fell asleep, and the physician performed the euthanasia procedure.[12]

Euthanasia violates the right to life

18. In 2009, the UN Human Rights Committee (UNHRC), which monitors compliance with the ICCPR, expressed apprehension about the high number of cases of euthanasia and assisted suicide. The Netherlands was "strongly urged" to revise its law in order to comply with the provisions in the 1966 International Covenant on Civil and Political Rights (ICCPR). In particular, the UNHRC expressed concern for the significant number of euthanasia and assisted suicide cases, and their annual progression. In addition, UNHRC asserted that some modalities raised questions about the Dutch law that allowed a doctor to terminate a patient's life without seeking a judge's opinion, and the fact that the second medical opinion required by law is obtainable via an emergency phone line.[13]

19. Article 6(1) of the ICCPR states that "Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life." The text, by its categorical formulation, intended "human being" in the broadest possible sense. The terms of the Covenant contain no language qualifying the term "human being" to exclude certain types or classes of human being, such as persons who are disabled or who have a debilitating illness. In fact, to do so would undermine the purpose for which the Covenant was created as stated in the Preamble of the Covenant.

20. The Netherlands should repeal the Termination of Life Act and affirm the right to life for all persons from the prenatal stage, regardless of disability or diagnosis. The Dutch government should also uphold the value of life until natural death, avoiding interventions that artificially induce death. Instead of promoting the death of the most vulnerable in their society, the Netherlands should increase access to quality medical care, including quality palliative case

to control pain and other symptoms, and to provide psychological, social, and spiritual assistance.

PRENATAL SCREENING FOR DISABILITIES AND SELECTIVE ABORTION

Background

21. Down syndrome is a condition that can be diagnosed before birth and has no known cure. The condition of individuals affected by Down syndrome varies, and some aspects of the prognosis during pregnancy—particularly the degree of intellectual disability—remain unclear. While one person with Down syndrome may graduate from college, another may have difficulty expressing himself/herself verbally. Other aspects of Down syndrome include a higher incidence of heart defects that may require surgery to correct.

22. In 2017, the Netherlands integrated the Non-Invasive Prenatal Test (NIPT) as a first-tier screening offered to all pregnant women. The NIPT is a new type of genetic test that can potentially detect a range or genetic (chromosomal) conditions in an unborn child by analyzing the blood of the mother.[14] Therefore, the NIPT can detect, with reasonable accuracy, if a fetus has Down syndrome but not how this diagnosis will impact his or her life.

23. There is scientific consensus that environmental factors (education, lifestyle, a loving and supporting environment, etc.) greatly influence an individual's health and well-being. In countries with robust social services and relatively high per capita wealth, prospects are high for people with Down syndrome to receive the health care they need and find ways to meaningfully contribute to their societies, including through participation in the workforce. Their families likewise could receive support both from assistance from the government and from support groups of other families that have members with Down syndrome. Tragically, children with Down syndrome are becoming more and more rare due to selective abortion in the very countries best equipped to foster support and inclusion to them and their families.[15]

Prenatal screening increases bias against individuals diagnosed with Down syndrome

24. Rather than ensuring that the baby diagnosed with Down syndrome in utero receives the best possible health care, a prenatal screening that reveals Down syndrome often results in the termination of unborn baby’s life.

25. In fact, 10 out of 18 European countries are reported to have an average abortion rate of 88% after a diagnosis of Down syndrome.[16] In the Netherlands, the abortion rate of unborn babies after a Down syndrome diagnosis has ranged from 74% to 94% for the past 23 years.[17]

26. According to one 2013 study, one in four participants said that medical professionals encouraged them to abort their unborn baby after a Down syndrome diagnosis, and many reported receiving inadequate information.[18] Other studies confirm the prejudice of medical practitioners against bringing unborn babies to term after a Down syndrome diagnosis.[19]

27. When the government endorses and promotes prenatal screening for Down syndrome, like NIPT, prejudicial bias against children with Down syndrome increases resulting in their termination even though many individuals with Down syndrome have a high quality of life.

States promoting abortion as a solution to a Down syndrome diagnosis are at least partly responsible for individual choices leading to the disappearance of people with Down syndrome.

RECOMMENDATIONS

28. In view of the above, the Center for Family and Human Rights (C-Fam) recommends the following:

    (a) Take steps to follow international obligations to protect the right to life including in the prenatal phase, regardless of disability or diagnosis, and to uphold the value of life until natural death, avoiding interventions that artificially induce death. Affirm the protection of life at every stage of human development, irrespective of age, disability status, illness, or infirmity;

    (b) Repeal the liberal euthanasia law, namely the 2002 Act;

    (c) At a minimum, introduce effective safeguards that would prevent abuse of the provisions allowing euthanasia and, in particular, reviews that must be conducted prior to the carrying out of euthanasia;

    (d) Regulate the introduction of prenatal genetic testing, based on the principles defined in the Universal Declaration of Human Rights, the UN Convention on the Rights of the Child (Preamble and article 1), and the UN Convention on the Rights of Persons with Disabilities (articles 5, 10, 14, 15, 23, 25);

    (e) Strengthen programs to support individuals with disabilities, in particular Down syndrome, and conduct awareness-raising activities to inform families about support that exists in the event of such a diagnosis;

    (f) Allow the use of genetic testing solely to enhance human care and well-being, and not to discriminate against people on the basis of their genetic predisposition; and

    (g) Ensure that all patients are provided with high-quality palliative care.

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[1] *See* Alliance Vita (2017) "Euthanasia in the Netherlands." Available at https://www.alliancevita.org/en/2017/11/euthanasia-in-the-netherlands/.
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[3] *See above* Alliance Vita.
[4] Boztas, Senay (2020, July 19). "Dutch MP backs euthanasia for over 75s who are 'tired of life.'" The Times. https://www.thetimes.co.uk/article/dutch-mp-backs-euthanasia-for-over-75s-who-are-tired-of-life-z8bdp6685
[5] "Third evaluation of the Termination of Life on Request and Assisted Suicide Assessment Act" https://publicaties.zonmw.nl/derde-evaluatie-wet-toetsing-levensbeeindiging-op-verzoek-en-hulp-bij-zelfdoding/; *see* "Euthanasia in the Netherlands," Vita Alliance, https://www.alliancevita.org/en/2017/11/euthanasia-in-the-netherlands/, for further analysis.
[6] Regional Euthanasia Review Report, 2019. Available at https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports and *see* "Euthanasia in the

Netherlands," Vita Alliance, https://www.alliancevita.org/en/2017/11/euthanasia-in-the-netherlands/, for further analysis.
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[8] *See above* Alliance Vita.
[9] *Id*.
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[11] *Id*.
[12] *Id*.
[13] *See above* Alliance Vita.
[14] "What is noninvasive prenatal testing (NIPT) and what disorders can it screen for?" available at https://medlineplus.gov/genetics/understanding/testing/nipt/
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