

Eugenics and euthanasia – then and now

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A main objective of this article is to give a presentation of the widespread acceptance of eugenics in the twentieth century and to show how the German euthanasia programmes were embedded in eugenic ideology. A second objective is to challenge the notion that eugenics and the practice of euthanasia on disabled people disappeared forever with the ending of the Second World War. The main reason for asking this question is to be found in today's medical practices in relation to inherited disorders and impairments, practices comprising both what can be labelled 'eugenics light' and euthanasia on newborns with congenital disorders.

Keywords: eugenics; euthanasia; disability

Introduction

Eugenics was a powerful early twentieth century philosophy movement whose major aim was improving the 'human stock' by reducing the number of people considered hereditarily 'unfit'. One of the extreme consequences of eugenic ideology was euthanasia on children and adults that did not match the hereditary standards. Several countries, agencies, intellectuals, and lay people embraced eugenics during the first half of the twentieth century and supported measures such as forced sterilization to reduce procreation of the hereditary unfit. In Germany, the political climate favoured even more radical measures than sterilization of targeted groups such as disabled people. The Third Reich initiated large-scale operations to cleanse the country of 'life not worth living'. One main objective of this article is to give a presentation of the eugenics of the twentieth century and to show how the large-scale euthanasia project T-4 was planned and initiated in order to 'free' Germany and the Third Reich of disabled people. A second objective is to question the notion that eugenics and the practice of euthanasia on disabled people disappeared forever with the end of the Second World War and the closing of the Nuremberg trials. An important reason for revisiting eugenic ideas and the practice of euthanasia is to be found in today's medical practices in relation to inherited disorders and impairments.

Then – the ideological legacy

With the publication of his book *Hereditary genius: an inquiry into its laws and consequences* in 1869, the Victorian polymath Francis Galton, cousin of Charles

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Darwin, voiced a view on the value of human beings that had profound impact on our understanding of normality and the treatment of disabled people (see, for example, Grue and Heiberg 2006). One of Galton's thoughts was that humans differed in relation to character, disposition, energy, intellect, etc. At birth, humans received the 'talents' they would have throughout their lives – 'natural qualities' determined by inheritance and making up the civic or genetic worth of man. In 1883, 14 years after the publication of *Hereditary genius*, Galton coined the term eugenics, i.e., from the Greek for 'well bred'. The term implied the antonym dysgenics 'ill bred'. The eugenic movement initiated by Galton was based on the simple doctrine that mental characteristics such as intelligence and diligence pass across generations in the same way as physical traits such as blue eyes do. Galton considered philanthropy and public health measures as squandering money (see, for example, MacKenzie 1981; Brookes 2004).

Eugenic ideology had a substantial impact on social policies in the first half of the twentieth century. Eugenic societies were established in most Western countries. The idea of limiting the number of the 'genetically inferior' in a population through the use of positive or negative eugenic means became widely accepted in a number of countries and by influential people. Among other groups, intellectuals, writers and poets like H.G. Wells, V. Wolf, W.B. Yeats, T.S. Elliot and F. Nietzsche, were intrigued by the idea of reducing the number of the genetically inferior. In a chilling passage in a letter to his friend Blanche Jennings in 1908, D.H. Lawrence explains how he would dispose of society's outcasts:

If I had it my way, I would build a lethal chamber big as the Crystal Palace, with a military band playing softly, and a Cinematograph working brightly; then I'd go out in the back streets and main streets and bring them in, all the sick, the halt and the maimed; I would lead them gently, and they would smile me a weary thanks; and the band would softly bubble out the 'Hallelujah Chorus'. (Referred to in Carey 1992, 12)

In particular, the following sentence in the quotation should be noted: 'they would smile me a weary thanks'. Since Lawrence's formulation conveys the impression that 'the sick, the halt and the maimed' would have been thankful to him for relieving them of their misery, this is a sentence linking eugenics to euthanasia. As we soon shall see this was a view shared by doctors later to be responsible for the killing of disabled people during the German euthanasia programme (Schmidt 2007).

During the first decades of the twentieth century, eugenic ideas and practices were found in most Western societies. In the mid-1930s, all the Nordic nations and a number of other Western nations had passed sterilization laws and eugenic programmes as part of a social policy experiment (Broberg and Roll-Hansen 1996). Genetics in the early 1900s set many of the parameters of these biological engineering programmes, embedded in the ideology of (optimistic) modernism. On the whole, it is safe to say that eugenic ideas and policies were widely accepted in the 1920s and onwards. In 1937, the British eugenicist Raymond Cattell, one of the fathers of the 'London School' of psychology, quoting Galton's prophecy that '300 years from now half the population will be mentally defective', argued that if England was to be an A1 nation the 'whole machinery of our medical services' had to be used, not merely 'preventive medicine' in the narrow sense (Cattell 1937, 12). As we will soon see, Germany was a country that 'used the whole machinery'.

Eugenic ideals would often be spoken of in parallel with the tending of a garden or the pruning of a tree. Only the most valuable plants, or parts of plants, had to be

taken care of and nurtured. In the 'perfect garden' there was no room for 'disabled' plants, and as a consequence they had to be removed. Analogously, the first period of eugenics meant sterilization; later it meant to be killed. As an example, the head doctor at the Kiev Pathological Laboratory, Dr. Gustave Schueppe, after the Second World War, compared the killing of disabled people with the pruning of a tree. Old or undesirable branches had to be removed in order to produce the highest yield (Donovan Nuremberg Trials Collection n.d.).

By 1920 the eugenics movement had a firm grip over the minds of many people in the Western world, but Germany was the country that most radically and violently implemented a eugenics policy and would therefore serve as the historical example of how the ideology of eugenics literally was lethal to disabled people. The historian H. Friedlander argues that one of the main reasons for Germany's radical policy in this field can be attributed to the political climate in the country during the first part of the twentieth century:

The political climate of the Weimar Republic, especially the ideology of the right-wing *völkisch* movement, provided a hospitable milieu where race hygiene could prosper. But most important, in January 1933 the National Socialist German Workers' Party (NSDAP) captured the German government. This assumption of power by the Nazis, the most radical *völkisch* movement, made the implementation of the race hygiene utopia possible. (Friedlander 1995, 16–17)

Genes versus germs

Francis Galton's main issue was to improve the quality of 'the human stock'. He defined the term 'eugenics' thus: 'Eugenics is the study of the Agencies under social control that improve or impair the racial qualities of future generations either physically or mentally' (Galton 2005; MacKenzie 1981). According to this definition, the aim of eugenics is to identify agencies that either improve or impair the racial qualities of the population. The term 'under social control' implies the participation of the state. According to this understanding, the implementation of measures such as sterilization laws (negative eugenics) and policies targeted at increasing procreation among 'valuable citizens' (positive eugenics), can be seen as eugenics as long as these measures are initiated or supervised by the state or other bodies under social control. At first glance, the definition is reminiscent of the historical aims of public health, which will also prove to be the case even though the relationship between them is a neglected subject of study. Despite their differences, public health agencies and eugenics organizations often overlapped in goals, methods, programmes and personnel. According to Pernick (1997) the conflict between eugenics and public health was mainly due to different interests, methods and values. They were two competing medical specialities. How infectious diseases should be fought was one of the main areas where they differed. Public health officials argued for measures such as water filtration and vaccination in fighting diseases such as tuberculosis and diarrhoea. Eugenics accepted the fact that germs were necessary to cause these diseases, but they strongly argued that hereditary resistance was the best way for cure and prevention in the long run. They stressed that the resistance of individuals to diseases was inborn and hereditary. Eugenics could be expanded not just to include germ fighting but most of the issues of concern within public health. Even if eugenics aimed at improving heredity, the meaning of heredity reached far beyond the genetic understanding of the time. Calling a trait hereditary only meant that 'you got it from

your parents'. It did not matter whether it was transmitted by genes, germs, precepts, or probate. This expansive definition of heredity held the parents responsible. With this understanding of heredity, eugenics meant not just having good genes, but also being a good parent, raising good children – that is, contributing to the promotion of good health for the generations to come. This understanding of eugenics was virtually synonymous with public health (Pernick 1997). Eugenics and public health should be seen as in cooperation rather than in competition. Public health could continue to concentrate on preventing people from dying, even the 'unfit' so long as eugenics prevented them from passing on their defects to their children. Pernick (1997) points out that some supporters of public health even drew a parallel between eugenics, euthanasia and the practice of killing infectious animals in order to protect the public from diseases. Key figures within public health opposed euthanasia, but some public health specialists were often quoted in the press as favouring the death of impaired newborns.

Even for ranking of 'races', some voices within the public health movement joined the views advocated by supporters of eugenics. The views of J.G. Wilson, a public health doctor and chief medical officer in charge of examining immigrants at Ellis Island, New York, can serve as an example. Wilson voiced some scepticism about eugenics and doctors who, in his view, too readily embraced eugenics. In a rejoinder in the *New York Times* in 1912 he attacked the views on heredity of a colleague, Dr. Hutchinson, who favoured eugenics. However, his attacks were not primarily grounded in morality or politics, but in what Wilson considered the lack of practical application of the laws of heredity. That is, the overall aim of eugenics, namely to reduce procreation among the feeble-minded or the mentally ill. In an article entitled: 'A Study in Jewish Psychopathology', published in 1913, he states:

If the science of eugenics deserves any practical application at all, it should insist upon a careful study of the every-day violation of its cardinal principle by a whole race who persistently refuse to practice the very doctrine which is essential to the preservation of a sound and healthy mentality. I refer to the Jews. . . First the Jews are a highly inbred and psychopathically inclined race. Second the prevalence of mental affections among them is almost entirely due to heredity. (Wilson 1913, 265)

Pernick (1997) argues that it may be important to acknowledge the fact that some of what was done in the name of eugenics was also done in the name of infection control and public health, and that some public health figures supported euthanasia. As a general observation, we could argue that there was no clear-cut line between physicians supporting the eugenic ideology and physicians working within the field of public health – one important reason being that there were different strands of eugenics and that eugenics in one version or another was accepted by a substantial part of the population in a number of countries.

The widespread acceptance of eugenic ideas outside Germany was also the reason why German physicians on trial in Nuremberg could refer to American examples to show that the task of getting rid of 'inferior elements' was not a mission unique to Germany (Schmidt 2007). Some arguments in defence of their actions were arguments that probably could be echoed by some of the American prosecutors, themselves perhaps tainted by eugenic ideas. To a large extent they were right, since the United States arguably was one of the countries where eugenic ideas and eugenic practices were both widely accepted and widely implemented during the twentieth century (see Black 2003).

Euthanasia and the T-4 programme

The German euthanasia programme started in September 1939 at a time when about 375,000 individuals had already been forcefully sterilized, among them people with psychiatric disorders, epilepsy, Huntington's disease, blindness and alcoholism. The women were mostly sterilized by the use of injections into the uterus; this while they routinely underwent gynaecological examination. Men were often sterilized by the use of x-rays. One popular method was for the men to be made to stand in front of a desk with a powerful x-ray machine hidden on the other side of the desk. While filling out a form they would receive high doses of radiation resulting in sterilization and quite often burns (Friedlander 1995).

In Germany, the idea of removing 'inferior' people, by having them killed, can be traced to the psychiatrist Alfred Hoche (1936). During the Weimar Republic, he was one of Germany's leading voices advocating the killing of severely handicapped people. Hoche strongly believed in the legality and moral justification of euthanasia. So did Karl Brandt, a medical doctor later to become Hitler's personal physician and main leader of the German euthanasia programme. Prior to a meeting in Freiburg in 1926 between Hoche and Brandt, the latter had been acquainted with Hoche's views on euthanasia by reading the famous tract 'Permission for the destruction of life unworthy of life', that Hoche had written together with the lawyer Karl Binding. The book had been published in 1920. According to the historian Ulf Schmidt (2007), this tract was by far the most important contribution to the debate on euthanasia in Germany. Hoche and Binding argued that 'incurable idiots' and the 'mentally dead' placed a financial and emotional burden on relatives, the community and the state. No money should be spent on 'inferior elements', they argued. Hoche and later Brandt applied the concept of the social organism developed by the British sociologist Herbert Spencer to the mentally ill (Schmidt 2007). Spencer saw the state as an organic entity in which the mentally ill were parts of the 'body politic' that had become damaged and useless, i.e., to be removed.

According to Schmidt, the medical profession, by and large, was not very impressed by Hoche and Binding's book. A number of doctors favoured sterilization of 'the inferior', but the killing of patients was quite another matter. However, the debate that followed the publication of Hoche and Binding's book placed euthanasia on the medical agenda and in Hitler's mind, since he too had read it (Hitler 1966). Here it remained until Hitler decided to initiate the 'euthanasia' programme in September 1939, with Karl Brandt in charge of the programme together with Philipp Bouhler, head of Hitler's private Chancellery KdF (Kanzlei des Führers). Besides being Hitler's personal physician, Karl Brandt became one of the most influential people within the German health system during the Second World War. In particular, he played a central role in the German programme 'to dispose of the genetically inferior'.

Hoche's teaching on the process of dying provided an intellectual and moral basis for Brandt when he later implemented the euthanasia programme together with Bouhler. For Hoche, dying was not difficult, nor was it something one had to be afraid of since humans suffered pain and agony throughout life. He pointed out that unnatural processes of dying, for example drowning, hanging, or gas poisoning, were not 'unpleasant' (Hoche 1936). Schmidt (2007) argues that Brandt may well have remembered Hoche's writings on the process of dying when he decided which killing method to use during the euthanasia programme – poisonous gases.

According to Schmidt, the euthanasia programme was part of a eugenics project to get rid of 'the inferior'. It was also part of a wartime measure to save food and bed-space in military and civilian hospitals. In the Nuremberg trial, Brandt downplayed the eugenics part of the programme, stating that the introduction of the euthanasia programme had been dictated by purely human considerations. The main issue was not primarily to remove people from society, but to free patients from their suffering. He defended his actions during the trial, as did other medical doctors, claiming human considerations for the sick and disabled as their main motive for taking part in the killings. Different sources (e.g., Schmidt 2007; Friedlander 1995; Lifton 1986; Evans 2004; Foss 2006) hardly support such claims. Even if doctors taking part in the killings were convinced that their deeds were an act of humanity, the euthanasia programme was part of a eugenics project aimed at reducing the number of 'inferior people' in the Third Reich. The use of medical doctors in this endeavour may have been triggered by a conception of doctors as 'surgeons of the people' cutting off and removing the 'infected' and 'unhealthy' parts of the social organism – the disabled, homosexuals, alcoholics, Gypsies and Jews.

Karl Brandt and Philipp Bouhler were personally entrusted by Hitler to organize and implement the euthanasia programme. However, according to Schmidt (2007) the origins of the programme are complex and scholars are still arguing over how it actually started. But even though the origins of the programme are uncertain, we have a clear idea with whom it started, namely with the most defenceless members of Germany society, disabled children.

Testimonies given after the war agree that one severely impaired child served as the pretext for Hitler initiating the programme (Schmidt 2007; Evans 2004; Friedlander 1995). The child, a boy called 'Knauer', was severely impaired – blind, with one leg and part of an arm missing. Hitler and Brandt gave in to the fathers wish to end 'the miserable life' of Knauer. After being informed by Brandt about the boy, a small group of middle-ranking government officials discussing the issue of euthanasia at KdF started a more detailed planning operation and in September 1939 the euthanasia programme for children was launched. In late autumn or winter 1939, Hitler signed the only document linking him to the killings. The adult euthanasia programme was initiated some time after the killing of children had begun. The operation became known as T-4 after the street address of the main office for the operation, Tiergartenstrasse 4.

It is hard to tell exactly how many disabled children and adults were killed during the period September 1939 to May 1945. Estimates vary from 275,000 to 500,000 (Schmidt 2007; Evans 2004). The number of people included in the programme will also vary depending on the geographical areas included. For example, somewhere between 110,000 and 140,000 were killed by the Nazis at the Kiev Pathological Laboratory in the Soviet Union alone.

It is important to remember that even though a substantial number of disabled people were killed during the euthanasia period, several authors have pointed out that these organized killings were not accepted or welcomed by large groups of Germans. One of the main reasons was of course that a number of ordinary Germans had a disabled family member or knew of disabled persons who had suddenly disappeared, later reported to have died in an institution which, in reality, was one of the killing centres for disabled people. Hitler, Bouhler and Brandt, and other leaders of the T-4 programme, were aware of the population's negative sentiments in relation to the killings, and this was probably one of the main reasons for keeping the

operation as covert as possible. No laws legitimizing the killings were ever passed, and it was Hitler's private chancellery KdF, not one of the official chancelleries, that was responsible for initiating and coordinating the killings. The operation of the euthanasia programme was meant to be as covert as possible, but official propaganda was frank on the issue of euthanasia both before and after the programme had been implemented. An example of how propaganda was used is this excerpt from a textbook for students in 1935:

To keep a mental patient costs approximately 4 RMs a day, a cripple 5.50 RMs, a criminal 3.5 RMs. In many cases a civil servant only has about 4 RMs, a salaried employee scarcely 3.50 RMs, an unskilled worker not even 2 RMs a head for their families. (a) Illustrate these figures with the aid of pictures. According to conserve estimates, there are about 300,000 mentally ill, epileptics, etc. in (asylums in Germany). (b) How much do these people cost to keep in total at a rate of 4 RMs per (person)? (c) How many marriage loans at 1,000 RMs each could be granted (per annum) from this money? (Referred to in Evans 2004, 87–88)

The people involved in the euthanasia programme wanted it to be a covert operation but it is important to acknowledge the fact that it was a well-planned large-scale operation aimed at reducing the number of 'inferior' people in the Third Reich. The programme was firmly embedded in the eugenics ideology of the time and hence in the modern vision of controlling nature. Being a political project, knowledge questioning the scientific bases of eugenics theory was overlooked or silenced. As an example, we know that at the time the euthanasia programme started, scientists had already discovered that one genotype corresponded with a number of variations in the phenotype (Johannsen 1911). Symptoms regarded as pathological might arise from interaction with surrounding conditions and therefore one genotype could not always be derived from the phenotype. Such findings stood in sharp contrast to the theoretical basis of eugenics. In 1917, the Danish geneticist Wilhelm Johannsen published a book dealing with questions of heredity, arguing that: 'The complexity of society makes it impossible that one single human type should be the best. We need all different types of humanity' (Broberg and Roll Hansen 1996, 25). Johannsen joined the Permanent International Commission on Eugenics in 1923 but he did not approve of 'the haphazard sterilization methods' applied in the United States. Just as many geneticists of his time, he was inclined to accept eugenic measures where the procreation of individuals with strongly flawed genotypes was prohibited. However, such measures had to be grounded in scientific evidence and not in outdated ideas of the relationship between genotypes and phenotypes (Broberg and Roll Hansen 1996).

Now

According to Pernick (1997) and Jacobsen (2007), parallels between the old eugenics and what we might broadly refer to as modern public health, genetics and biomedicine are stronger than we care to acknowledge. We may suffer from a cultural amnesia about what can be identified as contemporary ideas and practices that may be rooted in a eugenic view of life and the acceptance and value of human variance. Today, one could argue that combating disease supplies the perfect moral justification for pursuing a gentler 'eugenics quest' than in the first half of the twentieth century.

The eugenics of the twentieth century highlighted the clash of interests that comes about when a society over-rides the rights of individual members in the best interests

of all (Badcock 2003). Leaving morality aside, even from the point of view of biology and genetics, modern insight has revealed that such collective interests are difficult to identify (see for example, Leroi 2003; Undlien 2005). Present-day attitudes clearly favour the right of the individual to make his or her choices within the field of reproduction. There is no climate for a policy enforcing people to make decisions they do not approve of. Nevertheless, in a more individualistic and seemingly voluntary manner, what could essentially be labelled eugenics continues to be practised. A few examples of such practices are addressed below.

Tay-Sachs disease (TSD) is a genetic disorder where one-in-thirty American Jews is a carrier. Tay-Sachs is an autosomal recessive monogenic genetic disease, which means that to get the disease a child has to inherit two affected genes, one from each parent. There is no cure or treatment, but a simple blood test can establish who is a carrier and thus establish the likelihood of having an affected child if persons with the gene marry. By 2002, about 38,000 carriers had been screened and an unknown but probably significant number of Tay-Sachs' fatalities avoided in a voluntary programme (Badcock 2003). Another genetic screening programme for Tay-Sachs disease and cystic fibrosis (CF) among Jewish high school students in Australia identified carriers of both diseases (Barlow-Stewart et al. 2003). The main justification for initiating the programme was to give people an accurate assessment of the future risk of having children with conditions such as TSD or CF and, furthermore, to give couples at risk the opportunity to explore their reproductive options, which could include prenatal testing, adoption, sperm or egg donation and pre-implantation genetic diagnoses. There are examples of Jewish communities where marriage between two carriers of affected genes is not allowed due to the risk of giving birth to a child with the disorder (Heiberg 2008).

In a number of countries screening programmes have been initiated to identify carriers of different genetic disorders. Some of these are single-gene disorders, but most are more complex and demand the participation of several genes and/or environmental stimuli. However, the major parts of known genetic disorders are transmitted by autosomal recessive inheritance. Most of these disorders are rare and rather than launching expensive screening programmes a vast number of genetic tests have been developed and marketed on a commercial basis. Today, more than 1,000 different gene tests are available and one of the major arguments for applying the tests is to 'allow families to avoid having children with devastating diseases or [to] identify people at high risk for conditions that may be preventable' (Human Genome Project n.d.). Genetic testing, either carrier testing or prenatal testing, and screening programmes are measures aimed at reducing the number of children born with genetic disorders. Hence, testing for different inherited genetic disorders is a helpful means for parents when making the decision about having a child and what kind of child. This parental freedom to choose echoes the principle of autonomy so highly valued in Western cultures. The importance and ethical legitimacy of this principle can in consequence promote a 'eugenics of the free market'.

Euthanasia revisited

Today a soft version of what can be described as eugenic measures is practised in several countries. General public health measures aimed at reducing health risks for the foetus during pregnancy and different targeted measures to reduce the number of children born with specific disorders, i.e., Tay-Sachs disease, cystic fibrosis (CF) and

Spina bifida are carried out. The main rationale behind such measures is clearly to reduce the number of children born with impairment. Most people would probably find this version of eugenics 'light' acceptable, even welcome. However, once such measures are accepted, the question of which health conditions are 'acceptable' and which are not readily arises. Without an ongoing debate and close monitoring of what measures are applied and the ethical legitimacy of these measures, we might find that even this soft version of eugenics could be the starting point of a slippery slope ending with euthanasia on disabled children.

The Netherlands is a country presently practising euthanasia on disabled children and this case of The Netherlands can consequently serve as a starting point for some concluding comments. Euthanasia for fully competent persons older than 16 years of age has been legally acceptable since 1985 (Verhagen and Sauer 2005, 2007) and is also implemented. Here we shall focus on liberate life-ending procedures for children below 16 years of age, mainly newborns and infants, persons that cannot express their own will. In The Netherlands, as in all other countries, ending someone's life, except in extreme conditions (like war and capital punishment) is considered to be murder. However, every year between 15 and 20 newborns are euthanized in The Netherlands without the doctors responsible being prosecuted (Verhagen and Sauer 2005). Other sources operate with the number of about 100 children per year (Griffiths, Weyers, and Adams 2008). The explanation for this situation may be found in the Groningen Protocol (Verhagen and Sauer 2005). Legal control over euthanasia in newborns is based on the doctor's own reports, even though this is followed by an assessment by criminal prosecutors. The protocol describes in detail the requirements that must be followed in the case of euthanization of a child and information supporting and clarifying the decision about euthanasia must be given. Up until now, no doctor following the protocol has been legally prosecuted for performing euthanasia on a child.

For euthanasia to be carried out, the protocol requires that 'The diagnosis and prognosis must be certain. Hopeless, unbearable suffering must be present. The diagnosis, prognosis and unbearable suffering must be confirmed by at least one independent doctor. Both parents must give informed consent. The procedure must be performed in accordance with the accepted medical standards' (Verhagen and Sauer 2005).

However detailed the protocol, the decision to euthanize a newborn will always be a question of the doctor's judgement. In a way it could be argued that the protocol represents a sort of 'governance/acceptance by detachment' in relation to the practice of euthanasia. No official body has approved of or sanctioned the killings. However, when no one is brought to trial for euthanizing children, the practice must somehow be in line with the ethical views of those in power to stop it or let it pass.

Newborns for whom euthanasia might be considered are those destined to survive and able to ventilate on their own, but who will have a very poor quality of life with no known prospect of improvement (Costeloe 2007). Examples of disorders that may trigger a decision to euthanize the child include malformations such as serious Spina bifida and pre-term children whose impairments become apparent after recovery from respiratory problems. In an evaluation of euthanasia of newborns in The Netherlands, 17 out of the 22 cases investigated were children with Spina bifida. Lindeman and Verkerk argue in favour of the protocol in the following way:

The whole point of the protocol is to help physicians end the lives of newborns who are so severely afflicted that neither their dying nor their living should be prolonged. That being the case, the pertinent distinction is not between babies who will die and those who could live, but between babies for whom life-ending decisions should be made and those for whom such decisions cannot be morally justified. In bringing within its compass babies who are in no danger of dying – and, indeed, with proper care could live to adulthood – the protocol is even more radical than its critics supposed. (2008, 4)

Later in the same article they stress that: ‘To put it as plainly as possible, the protocol is not intended for disabled babies with even modest prospects for lives free of intense suffering’ (2008, 4). According to Lindeman and Verkerk (2008, 8), parental attitudes and love for their children constitute a guarantee against ending a disabled child’s life:

Nevertheless, we believe that because parents typically love all their children, regardless of the children’s medical needs, and because they are especially well placed to make judgments about the acceptability of a given quality of life for their babies.

As a comment on this ‘belief’ it is worth noting that not all parents love all children. The conditional nature of parental love (in relation to disabled children) has been convincingly described by Meira Weiss (1994) in her book *Conditional love, parent’s attitudes towards handicapped children*. Lindeman and Verkerk use their belief in parental attitudes towards their disabled children as an argument against the potential misuse of the protocol, but in some cases, parental attitudes do not necessarily secure the rights of disabled children.

Today, The Netherlands and Belgium are the only two countries in the western world where euthanasia is legal. For a more comprehensive and detailed discussion of the legal status of euthanasia in European countries interested readers should consult Griffiths, Weyers and Adams (2008). In relation to children, The Netherlands has not passed any laws permitting euthanasia. Instead, the Groningen protocol has been introduced to secure the decisions and procedures in relation to this question. In Belgium, lawmakers have announced plans to propose an extension to the country’s euthanasia law to allow the procedure for those under the age of 18. In the UK, the question of euthanasia on severely impaired newborns was raised in a report of the Nuffield Council of Bioethics in 2006. The conclusion of the report is that there is a clear and substantial difference between, on the one hand, withholding or withdrawing treatment of critically impaired newborns and, on the other, actively ‘putting them to sleep’. The group responsible for the report is not in favour of the latter alternative. The group’s view on euthanasia is supported by several paediatricians and neonatologists (see for example, Costeloe 2007). An editorial in the *Journal of Medical Ethics* (April and Parker 2007) indicates that there might be a difference of opinion in relation to this issue within the British medical milieu.

So far, it can be concluded that the issue of euthanasia is still with us and that there are indications of its gaining momentum as a morally acceptable measure dealing with seriously impaired children within the health care system. There are several reasons why this is a questionable development that should be carefully monitored, and, as a concluding part of this article, here are some of them.

Slippery slope

According to Costeloe (2007), one reason for the rejection of euthanasia as a therapeutic option is that active killing of newborns may be seen as a ‘slippery slope’

towards its wider use. Besides, it is extremely difficult with certainty to tell how a pre-term child will develop. Further on, many congenital genetic disorders may vary and no one can with absolute certainty predict the future life of a child with, for example, severe Spina bifida. A person's quality of life in the future is an extremely problematic criterion for deciding for or against euthanasia. Quality of life (QoL) is not an objective or precise concept. If any conclusion can be drawn from the vast body of research within this field it must be that even if a person's health condition may be closely linked to that person's QoL, it is not possible to make any objective statements about how much and in what ways. Proponents of the Groningen protocol seem to equal QoL with health and medical suffering. However, any person's QoL is closely linked to a number of other factors, e.g., family situation, living conditions, health care, friendship, etc. Once doctors start passing judgements on the future QoL of impaired people (primarily based on the person's medical status and health problems), they transgress the boundaries of their role as professionals trained to treat the sick and impaired.

When euthanasia is a therapeutic option and one of the indicators determining use of that option is the future QoL of a newborn, the important question arises: Who is capable of making an objective judgement about the future QoL of an impaired child, and what is an 'acceptable' QoL? The answers to these questions are all readily open to misuse owing to doctors' personal evaluations. These again are formed both by personal experiences and ideas and by how impaired people are being taken care of and treated by current practices in society as a whole.

Medical improvements

History has demonstrated the inadequacy of medical knowledge and technologies of a present time to predict the outcome of a life for a child born with a congenital. In less than a generation, life expectancies, and probably QoL too, for children born with disorders such as cystic fibrosis or Duchene's muscular dystrophy have improved dramatically. How present disorders may be treated in the future nobody knows.

Parental trust

Parents entrust their disabled or sick newborns to intensive care services often for several weeks. The stay is often longer than it is for intensive paediatric or adult care (Costeloe 2007). Parents do this because they have to and they are confident that the child will be taken care of and that in the case of a threat to life everything possible will be done by doctors and nurses to save the child. Their trust is based on the notion that the main objective of doctors and nurses is to preserve life. The use of euthanasia on newborns may erode that trust, as it did for a number of German parents asked to send their impaired child to one of the T-4 institutions – in order to receive better treatment.

Closing remarks

There are several reasons for keeping a watchful eye on the revitalization of euthanasia on newborns could be brought to the fore. The systematic killing of disabled people that took place in Germany in the twentieth century was quite clearly embedded in eugenic ideology. The eugenics of that period is not comparable to the

'soft' version of eugenics of today, i.e., eugenics of the free market that we can identify with in our time. Still it may favour an ideological climate where a person's value as human is closely linked to that person's health status. Once we start passing judgements on the quality of disabled children's lives, we may find that eugenic ideas and euthanasia are still part of our cultural heritage and therapeutic repertoire.

We should remember Karl Brandt's post-war explanations for his taking part in the euthanasia programme – and also those of other doctors in the German health system. Faced with their past, they now argued that their main aim was to help severely impaired people out of their 'misery'. To cure diseases and to relieve pain were their reason for taking part in the programme.

There is a need to keep a watchful eye on ideas that may allow this kind of 'humanity' and 'empathy' to surface in our societies once again. Arthur Caplan (2007), one of the most influential academics in the fields of health and bioethics, argues that in order to manage this we have firstly to challenge the view held by many contemporary scientists, namely the denial of any connections between what Nazi doctors or scientists did and their own activities and conduct. In his own writing:

Guilt by association has also played a role in making some bioethicists shy away from closely examining what medicine and science did during the Nazi era. Many doctors and scientists who were contemporaries of those put on trial at Nüremberg denied any connection between their own work or professional identities and those on the dock. Contemporary doctors and scientists are, understandably, even quicker to deny any connection between what Nazi doctors did and their own activities and conduct. (Caplan 2007, 71)

Secondly, we have to challenge the view held by many bioethicists, namely that what happened in Germany in the first half of the twentieth century was the deeds of 'madmen' on the fringe of society. We have to remember that especially Germany was one of the most advanced, 'civilized' and sophisticated countries in Europe and what happened involved a vast number of highly trained and professional doctors and other scientists.

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References

- April, J., and M. Parker. 2007. End of life decision-making in neonatal care. *Journal of Medical Ethics* 33: 126–7.
- Badcock, C. 2003. Eugenics. In *Encyclopedia of community: from the village to the virtual world*, Vol. 2., ed. K. Christensen and D. Levinson, 469–70. Great Barrington, MA. Berkshire Publishing Group.
- Barlow-Stewart, K., L. Burnett, A. Proos, V. Howell, F. Huq, R. Lazaeus, and A. Aizenberg. 2003. A genetic screening programme for Tay-Sachs disease and cystic fibroses for Australian Jewish high school students. *Journal of Medical Genetics* 40: 45–53.
- Black, E. 2003. *War against the weak: Eugenics and America's campaign to create a master race*. New York: Four Walls Eight Windows.
- Broberg, G., and N. Roll-Hansen, eds. 1996. *Eugenics and the welfare state. Sterilization policy in Denmark, Sweden, Norway, and Finland*. East Lansing: Michigan State University Press.
- Brookes, M. 2004. *Extreme measures. The dark visions and bright ideas of Francis Galton*. London: Bloomsbury.

- Caplan, A.L. 2007. The ethics of evil: The challenge and the lessons of Nazi medical experiments. In *Dark medicine. Rationalizing unethical medical research*, ed. W. Lafleur, G. Böhme and S. Shimanzo, 63–72. Bloomington: Indiana University Press.
- Carey, J. 1992. *The intellectuals and the masses. Pride and prejudice among the literary intelligentsia 1880–1939*. London: Faber and Faber.
- Cattell, R.B. 1937. *The fight for our national intelligence*. London: P.S. King & Son.
- Costeloe, K. 2007. Euthanasia in neonates. *British Medical Journal* 334: 912–3.
- Donovan Nuremberg Trials Collection. n.d. <http://www.lawschool.cornell.edu/library/donovan>.
- Evans, S.E. 2004. *Forgotten crimes. The Holocaust and people with disabilities*. Chicago: Ivan R. Dee.
- Foss, Ø. 2006. *Kampen Mot De Mindreverdige. Auschwitz, videnskapen og kirkens forræderi*. rhus: Aarhus Universitetsforlag.
- Friedlander, H. 1995. *The origins of Nazi genocide. From euthanasia to The Final Solution*. Chapel Hill: The University of North Carolina Press.
- Galton, F. 2005. *Hereditary genius: An inquiry into its laws and consequences*. New York: Prometheus Books. Originally published 1869.
- Griffiths, J., H. Weyers, and M. Adams. 2008. *Euthanasia and law in Europe*. Oxford: Hart Publishing.
- Grue, L., and A. Heiberg. 2006. Notes on the history of normality – reflections on the work of Quetelet and Galton. *Scandinavian Journal of Disability Research* 8, no. 4: 232–46.
- Heiberg, A. 2008. Personal communication with A. Heiberg, Department of Medical Genetics, Rikshospitalet, Oslo.
- Hitler, A. 1966. *Mein Kampf*. Copenhagen: Jørgen Paludans forlag. Originally published 1925.
- Hoche, A. 1936. *Jahresringe. Innenansicht eines Menschenlebens*. Leipzig: Felix Meiner Verlag.
- Hoche, A., and K. Binding. 1920. *Die Freigabe Der Vernichtung Lebensunwerten Lebens*. Leipzig: Felix Meiner Verlag.
- Human Genome Project n.d. http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetest.shtml.
- Jacobsen, K. 2007. The mystique of genetic correctness. *Logos* 6, no. 1–2. http://www.logosjournal.com/issue_6.1-2/main.htm.
- Johannsen, W. 1911. The genotype conception of heredity. *The American Naturalist* 45, no. 531: 129–59.
- Leroi, A.M. 2003. *Mutants. On the form, varieties & errors of the human body*. London: HarperCollins Publishers.
- Lifton, R.J. 1986. *The Nazi doctors. Medical killing and the psychology of genocide*. New York: Basic Books.
- Lindeman, H., and M. Verkerk. 2008. Ending the life of a newborn: The Groningen Protocol. *Hastings Center Report* 38, no. 1: 42–51. www.medscape.com.
- MacKenzie, D.A. 1981. *Statistics in Britain 1865–1930. The social construction of scientific knowledge*. Edinburgh: Edinburgh University Press.
- Nuffield Council on Bioethics. 2006. *Critical care decisions in foetal and neonatal medicine: Ethical issues*. www.nuffieldbioethics.org.
- Pernick, M.S. 1997. Eugenics and public health in American history. *American Journal of Public Health* 87, no. 11: 1767–72.
- Schmidt, U. 2007. *Karl Brandt the Nazi doctor. Medicine and power in the Third Reich*. London: Hambledon Continuum.
- Undlien, D. 2005. *Din unike arv – genetikk og helse*. Oslo: Aschehoug.
- Verhagen, E., and P.J.J. Sauer. 2005. The Groningen Protocol – euthanasia in severely ill newborns. *The New England Journal of Medicine* 352: 959–62.
- Verhagen, E., and P.J.J. Sauer. 2007. Physician medical decision-making at the end of life in newborns: Insights into implementation at 2 Dutch centers. *Pediatrics* 120, no. 1: 20–8.
- Weiss, M. 1994. *Conditional love, Parents' attitudes towards handicapped children*. London: Bergin & Garvey.
- Wilson, J.G. 1912. The cock-sure doctor. *The New York Times*, September 25. http://query.nytimes.com/mem/archive-free/pdf?_r=1&res=9903E6D71630E233A25756C2A96F9C946396D6CF.
- Wilson, J.G. 1913. A study in Jewish psychopathology. *Popular Science Monthly* 82: 264–71.