# Chapter 8 Bioethics and the *Krankenmorde*: Disability and Diversity



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Abstract Between 1933 and 1945, almost 300,000 people were murdered and 360,000 sterilized by the National Socialist (Nazi) regime under a group of crimes now collectively known as the Krankenmorde, the murder of the sick and disabled. Founded in narrow-minded and inconsistent accounts of a good and valuable life, the Nazi eugenic and "euthanasia" crimes were brutal and violent acts organized and executed by doctors, nurses and other professionals. Acknowledgement of this group of victims was delayed and obscured due to historical events as well as prevailing political and social attitudes toward mental illness and disability. As a result, the breadth of the Krankemorde crimes and its victims, its relationship to the Holocaust and its contemporary significance-to bioethics and society more broadly-is less recognized or understood than that of other Nazi medical crimes, such as the infamous experiments on prisoners. First presenting a history of the Krankenmorde and its aftermath in Germany and Nazi occupied territories, this chapter goes on to examine the value of bioethics having better knowledge of this part of its history and, in particular, engaging with its own epistemic constraints in relation to disability and ableism. These ideas are explored further in the context of contemporary bioethical issues related to the rights and treatment of people with disabilities, specifically the allocation of health resources. Throughout the chapter we seek to highlight the lives

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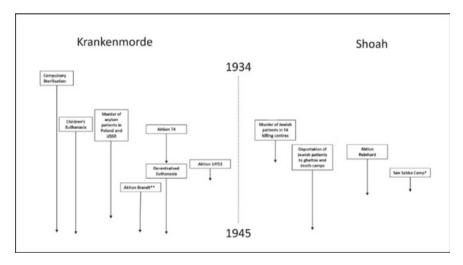
of *Krankenmorde* victims—those who survived and those who did not—all of whom have been historically overlooked and marginalized.

#### 8.1 Introduction

Approximately 300,000 people were murdered and 360,000 sterilized during the National Socialist (Nazi) regime (1933–1945) under a group of crimes now collectively known as the *Krankenmorde*, the murder of the sick and disabled.

As depicted in Fig. 8.1, the *Krankenmorde* describes multiple crimes perpetrated by the Nazi regime in order to persecute and exclude people with illness or physical, intellectual or psychosocial disabilities. Though the exact number of victims is still not known, it is estimated (Robertson et al. 2019, 23, 249; Hohendorf 2016; Schneider et al. 2014) that:

- Compulsory sterilization by vasectomy, tubal ligation, x-ray or radium irradiation (1933–1945)
  - 360,000 (perhaps up to 400,000 (Schneider et al. 2014, 9)) German citizens were forcibly sterilized. More than 5,000 people died because of sterilization procedures.
- Murder by shooting, gassing, electrocution, lethal drugging, or starvation and other deliberately fatal abuse and neglect (1939–1945)



**Fig. 8.1** The historical relationship between the Krankenmorde and the Shoah (Robertson et al. 2019), p. 154

- 80,000–100,000 patients were killed in eastern Nazi-occupied territories such as Poland and the USSR.
- 5,000 children were murdered in the "children's 'euthanasia'" program.
- 70,000 people were killed in the *Aktion* T4 "euthanasia" program.
- 10,000–20,000 sick or incapacitated concentration camp prisoners were killed at T4 sites under the "special treatment" 14f13 campaign.
- At least 87,000 people were killed during a "decentralized 'euthanasia'" phase, and/or as part of the emptying of hospitals and nursing homes for military and civil defence functions under *Aktion* Brandt.

# 8.2 "Life Unworthy of Living"

Founded in inconsistent and economically functional accounts of a "good" and "valuable" life, the Nazi eugenic and "euthanasia" crimes were brutal and violent acts organized and executed by doctors, nurses and other professionals.

As has been described elsewhere (Robertson et al. 2019), the Krankenmorde originated from different political, intellectual, and historical factors. The most frequently cited precondition to the persecution of the disabled in Western culture was the eugenic discourse that pervaded academic and elite social circles beginning in the late nineteenth century. Originally attributed to the English polymath Francis Galton—"whose explicit goal was to create better humans" (Goering 2014) eugenics became a cause célèbre among social elites and the academy in many societies, which enabled exclusionary immigration policies and compulsory sterilization laws in multiple countries. While ostensibly focused on questions of how to eradicate genetic disease and disability, eugenics and racial hygiene were interwoven concepts that linked racism and ableism in public policy in many countries (Mitchell and Snyder 2003). In Germany, an influential twentieth century manifestation of these ideas was published in 1920 by jurist Karl Binding and psychiatrist Alfred Hoche. Their monograph, Die Freigabe der Vernichtung lebensunwerten Lebens ("Allowing the Destruction of Life Unworthy of Living"), expounded a concept of euthanasia for certain groups of people, which included an argument that an ill or disabled person's value was diminished if her social contribution was outweighed by the cost of caring for her (Robertson et al. 2019). Following Hitler's ascension to the Chancellorship and the Nazi Party's control of the Reichstag in 1933, eugenic and racist ideas flourished in public policy. As noted by Robert J. Lifton, National Socialism was as much a biological as a political movement (Lifton 1986). The Nazis trafficked in biological metaphors that enabled an extreme state paternalism, which extended from seemingly enlightened public health policy to genocide (Proctor 1999).

An under-acknowledged theme in the history of this time is the status of the German medical profession and its struggles for professional autonomy through the Wilhelmine (1890–1918) and Weimar (1918–1933) periods (Burleigh 1997; Robertson et al. 2019). The hegemonic influence of Nazi biological nostrums and the weaponization of eugenics and racism facilitated an enhanced status of *Ärzte* 

(doctors) in the Nazi state. German physicians were enthusiastic and early adopters of Nazism, none more so than psychiatrists (Lifton 1986; Haque et al. 2012). Under the *Aktion* T4 program and later the "decentralized euthanasia" phases of the *Krankenmorde*, psychiatrists were empowered to eliminate severely ill and disabled patients who had not benefited from the novel physical treatments introduced into the asylum system, which had arisen from the new biologism of psychiatrists such as Emile Kraepelin and Ernst Rüdin. This group of severely ill and disabled patients were themselves blamed for their failure to benefit from biological psychiatry and cast into a category of deadly clinical nihilism that led, ultimately, to their murder. In Germany and occupied territories, asylum directors routinely utilized their political master's virulent anti-disability agenda to purge the dormitories of their institution of the most severely impaired and treatment refractory cases.

Throughout the following historical account of the *Krankenmorde* crimes we have drawn attention to individual victims and survivors. As is discussed in more detail later in this chapter, the lives of *Krankenmorde* victims have until recently been overlooked, marginalized, and discredited. We respectfully seek to center their lives and experiences in this history. At the same time, we recognize the limitations of some sources of information about victims and of our roles as contemporary external observers.

# 8.3 Compulsory Sterilization

Forced sterilization steered our lives onto a completely unexpected course. We were children, young women and men who had the rug pulled out from under us. Klara Nowak.

The starting point of the aggregate of crimes that comprised the *Krankenmorde* is usually taken as the Reichstag's passage of the Law for the Prevention of Genetically Diseased Offspring in 1933. This mandated the establishment of a medico-legal apparatus in the form of almost 200 hereditary health courts that would, by the end of the war, have ordered the sterilization of up to 400,000 "genetically defective" people.

Under the law a person was considered "hereditarily diseased" on the basis of diagnoses of intellectual disability, schizophrenia, epilepsy, manic-depressive disorder, severe alcoholism, Huntington's disease, blindness, and/or deafness. Conscious of the lack of empirical evidence for their actions, doctors, public health officers, and health and social care institutions were involved in reporting people believed to have an "hereditary defect" and filing requests for sterilization, after which doctors and magistrates passed judgement in the courts, and gynecologists and surgeons performed the procedures (Schneider et al. 2014).

#### **BOX 1:** *Klara Nowak (1922–2003).*

Born in Buchholz, Berlin, on March 29, 1922, Klara Nowak had just begun training as a nurse when she was committed to a mental hospital. One of her brothers was also institutionalised for a time. In 1940, the borough health office of Pankow, Berlin, requested that both of them be sterilized. They were involuntarily sterilized at the Charité in Berlin in 1941. In 1945, Klara Nowak and her mother fled Berlin to Halberstadt. Her brothers and father did not survive the war.

Later she described her situation: "Forced sterilization steered our lives onto a completely unexpected course. We were children, young women and men who had the rug pulled out from under us." Like many other victims of compulsory sterilization, she never married. After she had finished training in her chosen profession, she worked as a nurse, first in the German Democratic Republic and later in West Germany. The medial consequences of her involuntary sterilization made further operations necessary. She was pensioned in 1974. She received a one-time payment of DM 5,000 as compensation for her compulsory sterilization.

Since the 1970s, Nowak had been trying to shed light on what had happened to her. A physician friend helped her find her patient file from the Charité. "We survived the massacre of the Nazi period. But after the war, very little changed for us. We still couldn't talk about what had happened to us." In 1987, she broke the silence. Together with the psychiatrist Klaus Dörner, she founded the *Bund der "Euthanasie"–Geschadigten und Zwangssterilisierten* (BEZ), the alliance of compulsory sterilization victims and the families of "euthanasia" victims, which she chaired until 1999. She spoke openly about her wounds. Klara Nowak died on December 14, 2003 [Biographical details edited from Schneider et al. 2014, 189–190] (Image 8.1).

#### **BOX 2:** Wilhelm Werner (1898–1940).

Wilhelm Werner was born on September 18, 1898, in Schniegling near Nuremberg. His family lived in great financial distress, and, in 1902, his mother moved to a poorhouse with the children. His parents divorced in 1906. In 1908 or before, he was admitted to a Catholic institution, St Joseph's Home for the Feeble-Minded in Gemunden, Franconia, most likely because he was deaf. There he learned to read, write, do math—and draw. In 1919, aged 21, he was moved to the Werneck psychiatric hospital with a diagnosis of "imbecility" and lived there until 1940. He was forcibly sterilized between 1934 and 1938. On October 6, 1940, the first group transport from Werneck took Werner to the Pirna-Sonnenstein killing center, where he was murdered.

#### **Image 8.1**

Reichsgesetzblatt vom 25.
Juli 1933 mit der
Verkündung des "Gesetzes
zur Verhütung erbkranken
Nachwuchses"
[Proclamation Gazette from
25 July 1933 with the Law
for the Prevention of
Genetically Diseased
Offspring]



During his time at Werneck, Werner expressed his experiences of forced sterilization in 44 pencil drawings. The drawings were contained in a notebook that was saved for decades by an administrator from the asylum until acquired in the early twentieth-first century by the Prinzhorn collection at Heidelberg University (see <a href="https://prinzhorn.ukl-hd.de/museum/publications-of-the-prinzhorn-collection/wilhelm-werner/?L=1">https://prinzhorn.ukl-hd.de/museum/publications-of-the-prinzhorn-collection/wilhelm-werner/?L=1</a>). Marc Steene describes Wilhelm Werner's drawings as having a "theatricality... The story that these mannequins tell is harrowing, Werner directs a shocking series of tableaus, all drawn in a highly controlled way, exploring his sterilization. His characters are seeming puppets, victims lacking autonomy and under the control of cigarette smoking Nazi nurses" (Steene 2020, 2). He suggests: "We should not overlook the intention in Werner's work, this is a deliberate act of creation, an act of defiance and a statement of personal suffering drawn with great control and bravery" (Steene 2020, 2).

[Biographical details edited from Schneider et al. 2014, 54–57].

#### 8.4 Children's "Euthanasia"

Five thousand people died from complications of sterilization procedures; however, the *Krankenmorde's* most noted first victim was the infant boy Gerhard Kretschmer,

whose murder by barbiturate overdose in July 1939 in a Leipzig pediatric ward initiated the "children's euthanasia program" (Robertson et al. 2019). In February of that year, baby Gerhard was born blind, with phocomelia (malformed or absent limbs), and having seizures. When Gerhard's father petitioned Adolf Hitler for support for his child's "euthanasia," the Führer sent his escort physician Karl Brandt to examine the infant. Based on Brandt's assessment, Hitler authorized the clinic staff to euthanize Gerhard.

The "mercy death" of Gerhard would be a "threshold moment in the Nazi regime's attempted extermination of the disabled," setting in motion a large-scale pedocide that would eventually kill 5,000 children (Robertson et al. 2019). In this and other various phases of the *Krankenmorde*, the murder of children, adolescents and adults was conducted in cooperation with scientists—sometimes at the request of—who used their bodies for research.

#### **BOX 3:** *Elisabeth Jarosch* (1925–1940).

Elisabeth Jarosch was born in Lanietz, Upper Silesian, in 1925. Just one year after starting school, she was sent to a school for children with learning difficulties and finally removed from lessons completely. In 1935/6, Elisabeth, who experienced arbitrary twitches, was examined several times but a diagnosis could not be made. In 1936, she was admitted to Potsdam State Hospital, where doctors assumed that an organic brain disorder was the cause. Elisabeth fitted in well with institutional life. Although she usually played alone, she was friendly, sometimes even tender toward other children.

As of 1937, the entries in Elisabeth's file changed, stressing a lack of progress and an inability to communicate well. These negative comments also continued after the Potsdam institution moved to Brandenburg-Gorden. Because her symptoms could not be explained, scientists viewed her as an interesting case. She was one of more than 50 children from Gorden that were murdered for research purposes in the Brandenburg killing center on October 28, 1940. Her brain was made available to the Institute of Brain Research of the Kaiser Wilhelm Society in Berlin-Buch. At least 340 children and adolescents from the nearby Brandenburg-Gorden State Hospital were murdered in the Brandenburg killing centre.

[Biographical details edited from Ley and Hinz-Wessels 2012, 107].

# 8.5 Murder of Asylum Patients in Eastern Occupied Territories

Within a few months of Gerhard Kretschmer's death, SS and Wehrmacht units would perpetrate sporadic massacres of patients in psychiatric asylums and nursing homes in the newly occupied western Poland. Independent of the "euthanasia" activities

emanating from Hitler's Chancellery, from early September 1939 *Einsatzgruppen* units began committing mass killings of psychiatric patients in Poland by shootings and later in static and mobile carbon monoxide gas chambers–killing methods that would later be adapted on a larger scale for the extermination camps of the Shoah (Robertson et al. 2019; Evans 2010). These special units continued their murder of people with disabilities as part of mass killing operations in the Soviet Union following Germany's invasion in 1941. Henry Friedlander writes that although their focus was on the killing of Jewish, Roma and Sinti people and Soviet prisoners of war, the *Einsatzgruppen* did not overlook the disabled (Friedlander 1995; Evans 2010). This included the execution of people to clear institutions for wartime use, "for reasons of hereditary health", and in the course of testing different killing methods, for example, the use of dynamite and gas (Friedlander 1995). An estimated 100,000 people in the eastern occupied territories were murdered in this largely underacknowledged component of the Nazi persecution of the disabled.<sup>1</sup>

## 8.6 Aktion T4 and Sonderbehandlung 14f13

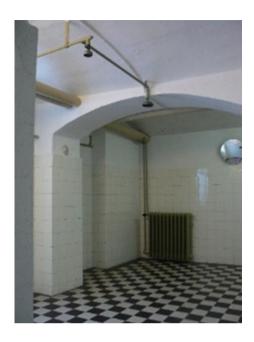
Meanwhile, in October 1939, Hitler wrote an order to the head of his Chancellery, Philipp Bouhler, and his physician Karl Brandt:

Reichsleiter Bouhler and Dr Brandt MD, are charged with the responsibility of enlarging the authority of certain physicians to be designated by name in such a manner that persons who, according to human judgement, are incurable can, upon a most careful diagnosis of their condition of sickness, be accorded a mercy death (USA v Karl Brandt et al).

Backdated to September 1, 1939, the day Germany had started the war, this order enabled the establishment of a secretive formal state system that empowered certain medical professionals and bureaucrats to decide which persons were "incurable" or "useless," what that meant to society, and what was to be "done" about it (Robertson et al. 2019, 142). Led by Bouhler and Brandt, the *Aktion* T4 "euthanasia" program—the bureaucracy for which operated out of a villa at number 4 Tiergartenstrasse, Berlin—commenced its work with the gathering of information about certain groups of patients from hospitals and nursing homes across the Reich. A central committee of medical assessors reviewed this registration information and any medical files to decide a person's death or survival. A person's work capacity and "curability" was often a factor in decisions. The names of patients condemned to death were placed on transport lists to ensure they were located and then taken to one of the six *Aktion* T4 killing centers, often via an intermediate institution to better organize and conceal these activities.

<sup>&</sup>lt;sup>1</sup> Less is known about the fate of patients in other occupied territories, such as France, where it is not agreed upon whether the estimated 48,588 patients who died of starvation in psychiatric hospitals between 1940 and 1944–half of all patients—was due to an intentional "euthanasia" policy or because of non-assistance due to the circumstances of war and Occupation (Hohendorf 2016; Mouchenik and Fau-Vincenti 2019; Lemoine and Stahl 2018).

Image 8.2 Bernburg gas chamber (Author photograph [Michael Robertson], 2015, Gedenkstätte Bernburg)



These initial coordinated phases of the *Krankenmorde* involved a bureaucratic process that identified and centrally registered victims, transported them to killing centers, and sought to deceive victims, their families and the broader community. At the killing centers—Brandenburg an der Havel, Bernberg, Hadamar, Pirna-Sonnenstein and Grafeneck in Germany, and Hartheim in Austria—victims were murdered in carbon monoxide gas chambers (Image 8.2). Their families would receive a bogus death certificate and sometimes (non-specific) ashes taken from the crematoria. "In effect, this operation provided the model for the Nazi's 'Final Solution'—the planned mass extermination of Europe's Jewish population and many other 'undesirables'" (Robertson et al. 2019, 23). More than 2,000 *Aktion* T4 victims were Jewish psychiatric or medical patients—killed solely because of their Jewish origin and regardless of their illness or ability to work—making them among the first victims of the Holocaust (Ley and Hinz-Wessels 2012). Some 90 T4 staff would also go on to put their experiences of mass killing to work at the Reinhard extermination camps of Belzec, Sobibor and Treblinka.

Aktion T4 was halted in August 1941–after the death of 70,000 people–however the criminal work of some of the killing centers continued under the program Sonderbehandlung (special treatment) 14f13. This additional killing phase–again co-led by Bouhler, this time with SS chief Heinrich Himmler–focused on the elimination of sick and disabled concentration camp prisoners who were no longer able to work. Selected for death by former T4 doctors, prisoners were transported to Bernberg, Pirna-Sonnenstein and Hartheim. The first 269 victims came from Sachsenhausen

concentration camp in June 1941 and were killed at Pirna-Sonnenstein (Robertson et al. 2019). The markings used to identify "seriously ill" prisoners included being forced to wear armbands inscribed with the word *Blöd* (indicating "feeble-minded") or to wear large signs around their necks that read "I am a moron" (Evans 2010, 66). Between 10,000 and 20,000 prisoners were murdered by the time the program ended in March 1943.

#### BOX 4: Otto Hampel (1895–1940).

Otto Hampel was born in Breslay in 1895 and trained to become a typesetter after school. For his contributions in World War I, during which he survived being buried alive, he was awarded the Iron Cross Second Class and the Hungarian Commemorative Medal of World War I. After the war, Otto Hampel soon found work as a sales representative in Berlin. He came into conflict with the law several times in the 1920s (burglary, receiving stolen goods and fraud). In the 1930s, he was also twice admitted to Municipal State Hospital and Nursing Home Berlin-Wittenau where he was treated for fever. In May 1937, Otto Hampel was sentenced by the district court of Berlin to nine months in prison on account of "continued homosexual acts." At the same time, the court ordered him to be housed in an institution. After he had served his sentence, Otto Hampel was transferred to the hospital in Berlin-Buch. He unsuccessfully applied several times to be released. On March 30, 1940, he was taken in a collective transport to the killing center in Brandenburg and murdered.

[Biographical details edited from Ley and Hinz-Wessels 2012, 101, 103].

#### **BOX 5:** Alma Pinkus (1898–1940).

Alma Pinkus was born the youngest child of a livestock dealer in Goritz an der Oder in 1898. After attending high school, she helped in the family home. Despite a serious stomach condition, she learned how to take care of babies and occasionally worked as a governess. After an acute gastric hemorrhage in the spring of 1931, she repeatedly expressed feelings of being "poisoned, hypnotised and influenced," after which she was committed to Landsberg/Warthe State Hospital in Brandenburg. Her treatment, with insulin, was stopped on account of her poor physical state. In March 1932, she was allowed home. Two years later she had to be admitted to Landsberg again, where she remained, with some breaks, until the summer of 1940. In July

<sup>&</sup>lt;sup>2</sup> One group deliberately included in the T4 killing was forensic patients, the number of which had increased considerably due to the 1933 "Law Against Dangerous Habitual Criminals and on Measures of Security and Recovery". The law allowed people to be committed to a hospital if "public safety" demanded it and also permitted "preventive detention", which the Nazi regime also used to persecute political opponents and social groups on the margins of society (Ley and Hinz-Wessels 2012, 99).

1940, she and all other Jewish patients at Landsberg were taken to an intermediate institution and then on to the Brandenburg killing center where they were murdered. Officially she died of "furuncle of the nose and meningitis in the 'Chelm Lunatic Asylum'" near Lublin on January 28, 1941.

[Biographical details edited from Ley and Hinz-Wessels 2012, 159].

#### **BOX 6:** Theodor Kynast (1904–1940).

Theodor Kynast was born June 28, 1904, and lived with his parents in Göppingen, Württemberg. As a young man he was diagnosed with schizophrenia and was admitted to the Christophsbad private sanatorium in Göppingen. On October 14, 1940, by order of the Württemberg Ministry of the Interior, he and 74 other male patients were transferred from Göppingen to the Württemberg sanatorium in Winnental. On November 29, 1940, 16 of the Göppingen patients, including Theodor Kynast, were transported together with patients from other institutions to the Grafeneck killing center and gassed there on the same day. The false death certificate issued by the Grafeneck registry office and the so-called "consolation" letter to the parents in Göppingen have been preserved in the original and are now in the Grafeneck memorial archive. They are dated December 3 and December 4, 1940. After his murder his parents received his personal belongings, among which they found a cookie into which he carved the words "Abt. Morder" [ward of murderers].

[Biographical details edited from Gedenkstätte Grafeneck Dokumentations Zentrum 2016; Bruggemann and Schmid-Krebs 2007].

#### 8.7 De-Centralised "Euthanasia" and Aktion Brandt

The current historiography of the *Krankenmorde* portrays it as progressing from a centrally coordinated process of killing selected victims in six dedicated killing centers with static gas chambers (*Aktion* T4), to a more murderous regionalised phase of killing in hospitals and asylums by starvation, poisoning or electrocution. This decentralized phase of "euthanasia" took place in more than 30 different state hospitals and asylums and also expanded the scope of victims to include the frail and elderly, laborers who had fallen ill, and injured or incapacitated soldiers (Robertson et al. 2019; Image 8.3). At Mesertitz-Obrawalde hospital, for example, an estimated 97% of patients—pre-existing patients and those transferred from other institutions—were murdered by overdose, in total approximately 10,000 people (McFarland-Icke 1999; Benedict et al. 2007). Many were dead on arrival at Obrawalde hospital or died soon after, particularly children (Benedict et al. 2007).

Aktion Brandt (1943–1945) describes the lethal displacement of patients from psychiatric hospitals and nursing homes for military and civil defense purposes, making space for wounded soldiers and for physically ill or injured civilians as urban



**Image 8.3** Page from register of deceased patients at the Eglfing-Haar institution (1944), where more than 330 children died by poisoning in a Kinderfachabteilung (special children's ward). Other Eglfing-Haar patients were also murdered by poisoning, neglect or malnutrition caused by a special "starvation diet" or were sent to the killing centres Grafeneck and Hartheim. (Author photograph [Edwina Light], 2013, Psychiatriemuseum am kbo-Isar-Amper-Klinikum München-Ost)

hospitals were destroyed in bombings. There is disagreement among historians as to whether *Aktion* Brandt was a sporadic process or a systematic revival of a centrally organized program to murder the sick and disabled–notably argued by Götz Aly among others–in addition to the regional "decentralized euthanasia" activities that occurred at individual hospitals and other care institutions after *Aktion* T4 ended (Aly et al. 1985; Aly 1989; Burleigh 1994; Schwarz 2002; Hohendorf 2016).

It was so-named because former T4 co-leader Brandt, now *Reichskommissar für das Sanitäts- und Gesundheitswesen* (Reich Commissioner for Sanitation and Health Care), managed decisions about and the coordination of the transfers of patients from areas affected by increasing air bombardments to the region's institutions (Schulze 2010). Schulze (2010) writes that despite the continuity of these events with *Aktion* T4, "there existed at that time no centrally managed extermination programme within which patients would be liquidated en masse in specially appointed institutions adapted for such a purpose."

It is estimated that after *Aktion* T4 stopped in August 1941–following growing public disquiet, direct protest from some community leaders, and the mounting demands of the regime's war in the East– at least 87,000 people in institutional care (perhaps 100,000 (Schulze 2010)) died as part of the *Krankenmorde*.

#### **BOX 7:** *Babette Fröwis* (1929–1943).

Babette Fröwis was born in Munich in July 1929. From birth, Babette demonstrated numerous feeding and settling problems and spent the first five months of her life in an institution for children with disabilities. Babette returned to live with her family and continued to show signs of significant developmental delay. As a child she suffered

numerous seizures and exhibited increasingly distressed behavior, including tearing out her hair and screaming uncontrollably. Babette's parents became concerned that her behavior posed a risk to her younger siblings. Pediatricians declared her an "imbecile" and "ineducable." In August 1934, Babette was placed in permanent institutional care at the Schönbrunn Sanatorium in the city of Dachau. She remained at Schönbrunn until late 1943. In early October the Schönbrunn medical director, a pediatrician named Dr. Hans-Joachim Sewering, informed Babette's parents that due to her behavior she could no longer be properly cared for at Schönbrunn. On October 23, 1943 Sewering signed a transfer order for Babette to be sent to the Kinderfachabteilung at the hospital in Eglfing-Haar on the outskirts of Munich. Babette Fröwis died there on November 16, 1943. In her Eglfing-Haar medical file an entry reads "inadequate food intake for five days, frequently chokes while eating. In the last few days tracheobronchitis. Died today." Despite this statement, Babette had been assessed as being of robust physical health when admitted to Eglfing-Haar three weeks earlier. The lies documented in her medical file were intended to conceal the fact that she had died after being overdosed fatally on a medication, most likely the barbiturate Luminal.

[Biographical details edited from Robertson et al. 2019, 209–210].

### 8.8 Krankenmorde Memory, Meaning and Bioethics

Acknowledgement of *Krankenmorde* victims was delayed and obscured for decades due to historical events as well as prevailing political and social attitudes toward mental illness and disability. Detailed accounts of delays to recognition of the *Krankenmorde* are provided elsewhere, describing barriers to acknowledgement and restitution (such as the division of Germany post-war, the scope of legal processes, and societal indifference), as well as recent activities to recognize the crimes, the victims, and the responsibilities for the perpetration and latter suppression of the crimes (Light et al. In press; Schneider et al. 2014; Robertson et al. 2019).

Post-war legal processes predominately focused on the Nazi's medical research crimes and although some *Krankenmorde* perpetrators were prosecuted, many were never held accountable. Alexander Mitscherlich's well-known 1949 account of the Nuremberg Doctors' Trial<sup>3</sup>—which indicted 23 doctors for various roles in medical experiment crimes and/or "euthanasia"—illustrates some of the early equivocation about the criminality of the *Krankenmorde*: "The granting of 'dying aid' in the case of incurable mental patients and malformed or idiot children may be considered to be still within the legitimate sphere of medical discussion," he wrote, suggesting that it was only of greater concern as the scope "moved more and more openly to purely political and ideological criteria for death..." (Mitscherlich and Mielke 1949, 117). The Nuremberg judges similarly appeared to take the position that the Nazi state had the right to implement euthanasia on medical grounds (Burdett 2011; Knittel

<sup>&</sup>lt;sup>3</sup> United States of America v Karl Brandt, et al., Nuremberg Military Tribunal (NMT) No.1.

2015). Among other contemporary scholars, Emmeline Burdett emphasises that the "dismissive and paternalistic assumptions and stereotypes about disabled people" at Nuremberg were not unique to that time or to those judges (Burdett 2011). She argues, "[I]t remains true that there is a widespread assumption that (a) people subjected to non-consensual 'euthanasia' are not in possession of any characteristics bar that of irredeemable suffering; (b) killing such people is simply not the same as the murder of another sort of person would be; and (c) the person or people in question do not suffer from being killed" (Burdett 2011, 8–9).

Politically, survivors, families and advocates have also had to fight against marginalization, discrediting and shaming (Light et al. In press). It was only in 1998 that a national law passed to overturn the hereditary health court sterilization orders (Surmannn 2014). In 2010, the German psychiatric profession officially apologized (Schneider et al. 2014), and in 2017 the Bundestag focused on the victims of the *Krankenmorde* in its annual Holocaust Remembrance Day, including an acknowledgment of decades of suppression and denial (Lammert 2017).

These themes have been echoed in the scientific literature. In her analysis of Krankenmorde historiography, Emmeline Burdett argues that study "has been hindered-if not totally prevented-by historians' casual dismissal of the murder of hundreds of thousands of people" because of an almost exclusive focus on protests against the "euthanasia" program and those who perpetrated this agenda (Burdett 2014, 39). Reviewing the literature from the 1950s onward, she builds on explanations (Kudlick 2003) for why historians and the general public doubt the criminality of "killing people who are frequently perceived to be a burden on society." Burdett argues that "historians have perceived the victims of the Nazi euthanasia programme in ways that are commensurate with the ways in which disabled people are perceived in their societies" (Burdett 2014, 39). Early studies of the Nazi period and medical crimes largely ignored the Krankenmorde, while in subsequent decades they focussed on protests against it (often in contrast to the lack of protest against other victims of Nazi criminality), public perceptions and reactions to it, and the roles and motivations of doctors and other perpetrators. These works treated it "as a dry ethical issue" and rendered the victims invisible, she says (Burdett 2011, 2014). Burdett points to later works (Burleigh 1994; Friedlander 1995; Evans 2010; Gallagher 1990) as examples of changes in historians' attitudes that have led to greater investigation of the Krankenmorde, which has "mirrored positive changes in social attitudes toward disability" (Burdett 2014, 48). These historical accounts have been central to much of the bioethical analysis of the Krankenmorde.

A unique challenge to the study of the *Krankenmorde* is emphasised by Susanne Knittel: how to center the voices of witnesses and survivors when there are few or no survivors (except of sterilization), there has been no community of memory, and key sources—sometimes the only documentary sources—of this memory are the medical records created by the perpetrators (Knittel 2015, 23). These questions are put in the context of the work of memory studies, but apply equally to other disciplines such as history, medical ethics and bioethics. Referring to the work of Snyder and Mitchell (2006), Knittel situates the silencing of *Krankenmorde* victims and survivors in the context of dominant Holocaust discourse and memory which "brackets off" the

"euthanasia" program, casts Nazi medicine as an "unprecedented aberration of the healing professions," and decouples the international eugenics movement from the Holocaust thereby reinforcing an "imaginary line between 'medical intervention' and murder" (Knittel 2015, 19,20,23). She sets out some approaches to this problem proposing an engagement with disability studies and the concept of "vicariousness"that "can go some way toward recovering and imagining these victims' stories" (Knittel 2015, 23). Throughout this chapter we have sought to highlight the words and lives of Krankenmorde victims-those who survived and those who did nothowever, we acknowledge the same limitations and ramifications of what we present here. They are mostly sourced from medical and state records. Furthermore, where we can look to first-hand expressions by victims about their experiences—such as the words of Klara Nowak, the art of Wilhelm Werner, and the message from Thomas Kynast-we must remain mindful that the meanings we attribute to them come from our own values as external twenty-first century observers. It is also important to draw attention to contemporary challenges, where patients/consumers and survivors have fought to have their experiences and voices centered within bioethics and health law discourses, particularly in relation to ongoing contests about coercive practices in mental health care and the treatment of people with intellectual or psychosocial disabilities more generally.

The need for a greater engagement by bioethics with disability studies and human rights has been emphasised by the UN Special Rapporteuer on the Rights of Persons with Disabilities, Catalina Devandas Aguilar, who in a 2019 report called for bioethics to move toward a "disability bioethics" or "disability-conscious bioethics" (United Nations Special Rapporteur on the Rights of Persons with Disability 2019). The report on ableism in medical and scientific practice states, "Unlike the widespread moral revulsion and outrage against comparable atrocities of the twentieth century, the significance of the eugenics movement and its impact on how societies continue to dismiss the value of the lives of persons with disabilities has long remained confined to disability circles" (pp. 3–4). It argues that ableism-defined as "a value system that considers certain typical characteristics of body and mind as essential for living a life of value"-continues to dominate important debates that impact the rights of people with disabilities, debates which often take place primarily in the field of bioethics (p.5). Acknowledging "a close but conflictual" historical relationship between bioethics and disability, the report says, "Much of the work in bioethics to date has been based on a thin or inaccurate understanding of the diversity, complexity, and socially embedded nature of disability." And while some bioethical work has begun to take into account the perspective of persons with disabilities, ableist views "dictate most bioethical discussions, from prenatal testing to assisted dying. They therefore fail to address the bioethical questions that actually concern persons with disabilities" (United Nations Special Rapporteur on the Rights of Persons with Disability 2019, 5). The report concludes that the "hegemony of ableism in society has perpetuated the idea that living with a disability is a life not worth living"-privileging prevention and cure over other responses to disability and limiting people's 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" (United Nations Special Rapporteur on the Rights of Persons with Disability 2019, 17).

Like Knittel (2015), Snyder and Mitchell (2006) and others, the UN Special Rapporteur's study highlights how relevant areas of bioethics—and other disciplines are made inadequate by the excision of the Krankenmorde from the history of the Holocaust, by any ambivalence about its status in the crimes of the Nazi period, and by ignoring the experiences and perspectives of people with disabilities. It would suggest that bioethics needs to know its history better and to turn some of its analysis onto itself in terms of disability and ableism. It draws attention to significant lacunae in some of the theoretical perspectives of bioethics, reflecting certain epistemic limitations to its work. As part of this, a shift is required from the idea that events like the Krankenmorde were one-off, local events from the past, not related to the current time or place. Writing more broadly about bioethics and disability, philosopher Shelley Tremain argued that despite the regularity of medical and scientific abuses upon various marginalized groups during the twentieth century, bioethicists have tended to cast such practices and programs "as anomalies and rarities, as disturbing relics of days gone by, and as disruptions in the history of an otherwise noble, emerging endeavor ... the scope of these critiques has for the most part been limited to arguments against a particular biomedical practice or the position of a certain bioethicist, leaving the historical conditions of possibility for the overall enterprise of bioethics unexamined and unchallenged" (Tremain 2020).

In an important report on disability and bioethics to the UN Rapporteur, Jackie Leach Scully and Tom Shakespeare highlight the significance of bioethics to people living with disability today (Scully and Shakespeare 2019). "Bioethics helps societies decide which sorts of interventions into and supports for disability are morally good. But we also note that disability is important for bioethics, in that the diversity of human bodies that can exist is a central focus of biomedicine's, and therefore bioethic's, attention," they wrote (Scully and Shakespeare 2019, 55). They concluded, "It is vital that bioethics acknowledges the limitations of its approach to disability, and that efforts are made to encourage more disability-inclusive bioethical work."

# 8.9 Disability and Bioethics

"The greatest involvement of bioethics with disability has been in areas that are very directly about life and death", write Leach Scully and Shakespeare, providing examples such as prenatal diagnosis, preimplantation genetic diagnosis and preconception screening to prevent the birth of children with disabilities; the reproductive rights and freedoms of disabled people; and issues at the end of life, such as assisted suicide, euthanasia and decisions about continuing medical treatment when a person is seriously ill or dying (Scully and Shakespeare 2019, 4). Other topics where bioethics contributes include healthcare rationing as it affects disabled people and the use

of biomedical technologies to normalize anomalous bodies or minds (Scully and Shakespeare 2019).

Euthanasia and medically assisted dying are examined in a separate chapter in this book. At the time of writing, voluntary assisted dying (euthanasia and assisted suicide) was lawful in 18 jurisdictions in eight countries. In Germany, political and cultural debates on the provision of assisted dying re-emerged after a Constitutional Court ruling in 2020 overturned a ban on professionally assisted suicide (Richter-Kuhlmann 2020; Hyde 2020; Ethikrat 2020). The sensitivity to legalizing euthanasia in Germany relates in part to the history of the *Krankenmorde* (Hyde 2020) and the Nazi regime's euphemistic use of the term "euthanasia" to describe its campaign of murderous violence, abuse and neglect of people with disabilities and others deemed unworthy of life.

The UN Special Rapporteur recommended that where member states permit assisted dying, they should implement strong measures to protect the life of people with disabilities on an equal basis with others (United Nations Special Rapporteur on the Rights of Persons with Disability 2019). In her 2019 report, the Special Rapporteur noted that assisted dying was a contentious issue within the disability community. "From a disability rights perspective, there is a grave concern that legalising 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" (United Nations Special Rapporteur on the Rights of Persons with Disability 2019, 9). Additionally, people with disabilities may decide to end their lives because of social factorsincluding loneliness, social isolation and lack of access to support services-or they may be vulnerable to explicit or implicit pressures, "including expectations from family members, financial pressures, cultural messages and even coercion" (United Nations Special Rapporteur on the Rights of Persons with Disability 2019,10).

Some of these concerns were highlighted in intense public debate in 2020 about proposed changes to existing medical assistance in dying (MAID) laws in Canada, which included criticism that the reforms would "single out disability" in a manner inconsistent with human rights and "promote stigma and prejudice against persons with disabilities and suggest that some lives are not worth living" (Legal and Constitutional Affairs Standing Committee 2020; Nicol and Tiedemann 2020; Lemmens and Krakowitz-Broker 2020). Philosopher Shelley Tremain's submission, strongly opposed to Bill C-7, expressed her concern that the bioethical advice to the Standing Committee represented "biased philosophical assumptions and contextually specific and socially-situated perspectives" (Tremain 2020). She was "deeply concerned that

<sup>&</sup>lt;sup>4</sup> Australia (Victoria, Western Australia, Tasmania (commencing 2022), South Australia and Queensland (commencing 2023)); New Zealand; the US (Oregon, Washington, Vermont, California, Colorado, Hawaii, New Jersey, Maine, District of Columbia, and Montana); the Netherlands; Belgium; Luxembourg; Canada (federal and Quebec); Colombia; and Switzerland (End of Life Law in Australia 2020).

a handful of bioethicists have represented their positions on MAID and expansions of it... as objective and value-neutral responses to the question of how Canadian society should treat disabled people who may feel hopeless, may be socially isolated, may live in poverty, and may lack social resources" (Tremain 2020). In her testimony to a Canadian parliamentary study of Bill-7, Catherine Frazee, Professor Emerita at Ryerson University School of Disability Studies and former Chief Commissioner of the Ontario Human Rights Commission, argued that there was no evidence to support claims about the assumed suffering caused by a disabling condition, unlike the suffering that is caused by social exclusion and deprivation such as those related to institutions and bureaucracies (Frazee 2020).

In the next part of this chapter, we examine a contemporary issue in bioethics—the allocation of health resources —where disability is a central feature and which also challenges and critiques the work of bioethics itself. The literature and cases presented below are not necessarily intended to be representative of all events or viewpoints. Rather they seek to highlight key issues and important perspectives around current events that are not always centered in bioethical discourses. In this way we hope the reader has opportunities to engage with some of the ideas raised in this chapter and to consider the ongoing legacies of the *Krankenmorde*.

#### 8.10 COVID-19 and the Allocation of Health Resources

The ableism I write about in my professional capacity became a frightening and damning reminder that I am dispensable in order to save 'real' people." Rosemary Kayess.

In July 2020, the memorial institutions commemorating the Nazi "euthanasia" crimes released a joint statement of concern about discussions being had during the COVID-19 pandemic about intensive care triage decisions for older people and people with prior illnesses or disabilities (Gedenkstätten zur Erinnerung an die nationalsozialistischen Euthanasie-Verbrechen 2020). The concern of the signatories-including those of the Bernburg, Brandenburg, Hadamar, Pirna-Sonnenstein and Hartheim memorials-was expressed against a background of their work conveying the history of Nazi crimes and dealing with current medical-ethical questions in educational programs and events." Following the publication of resource allocation recommendations by German medical societies, the representatives of these memorial institutions wrote that there was a "danger that the groups mentioned [seniors and people with disability] could be excluded from intensive care if the health system is overloaded." Though Germany had not yet had such a state of emergency, the group argued it was "more important now to discuss the ethical, medical and legal implications of triage decisions in a broadly societal manner and without time pressure." They called on the German Bundestag to take up the issue and to involve self-advocacy organizations for people with disabilities and the elderly in the discussion of whether the specialist societies' recommendations could guide action. "The establishment of regulations for triage decisions cannot be left solely to medicine," the representatives of these institutions said (Gedenkstätten zur Erinnerung an die nationalsozialistischen Euthanasie-Verbrechen 2020).

Similar concerns were raised in multiple countries, by disability, bioethics and human rights scholars, advocates and practitioners among others, as various guidelines for the allocation of pandemic critical care—or other potentially limited resources such as vaccines and therapies—suggested unjust and discriminatory criteria for excluding older people and people with disabilities (Goggin and Ellis 2020; Scully 2020; UN Committee on the Rights of Persons with Disabilities 2020; Disabled People's Organisations Australia 2020).

This was one of a "rolling series of interlocking threats to disabled people's lives" in the pandemic, according to US writer Andrew Pulrang, who captured a broader concern: "The COVID-19 pandemic has revealed much that is usually hidden. For people with disabilities, the most revealing and terrifying aspect of the crisis is the sharper, more critical view we are getting of long-standing strains of ableism in health care policy and medical ethics" (Pulrang 2020). Among suggestions for practical steps his readers could take to protect their rights should they get sick and need to go to the hospital in the US, which at the time had the highest global case incidence of COVID-19–(World Health Organisation 2020) Pulrang identified the #NoBodyIsDisposable campaign (Pulrang 2020). In addition to a "Know Your Rights" patient toolkit, the US-based coalition lobbied care providers, hospitals, and policymakers for policies to avoid discrimination in triage. Its messages of protest and solidarity included: "Don't let #COVID19 triage kill disabled, fat, old, HIV + and sick people!" and "#noICUgenics" (#NoBodyIsDisposable 2020).

In the Australian context, international experts in human rights, bioethics and disability studies together released a "COVID-19 Statement of Concern" which emphasised key rights and standards needed to underpin ethical decision-making (Disabled People's Organisations Australia 2020). Statement signatory and Vice-Chair of the United Nations Committee on the Rights of Persons with Disabilities, Rosemary Kayess, said they were "concerned that any increasing demand on critical health treatment and intensive medical care will require decisions to be made about life-saving treatment that could seriously undermine the rights of people with disability." Reflecting on her own experiences during the pandemic, Ms. Kayess stated elsewhere that "the devaluing of people with disabilities is embedded in law, policy and practice, prejudicing the decisions about who is deserving of critical health care and life saving measures. The ableism I write about in my professional capacity became a frightening and damning reminder that I am dispensable in order to save 'real' people" (Kayess 2020). At the global level, the United Nations Committee on the Rights of Persons with Disabilities expressed its "grave concern" at the devastating impacts of the COVID-19 pandemic on persons with disabilities, highlighting that, "pre-existing discrimination and inequality means that persons with disabilities are one of the most excluded groups in terms of health prevention and response actions and economic and social support measures, and among the hardest hit in terms of transmission risk and actual fatalities" (UN Committee on the Rights of Persons with Disabilities 2020).

In a paper examining the impact of disablism<sup>5</sup> on pandemic care decisions, bioethicist (and signatory to the Australian Statement of Concern) Jackie Leach Scully wrote: "One interpretation of this discrimination is a straightforward disvaluing of the lives of people with disability. In practice, it is more likely to be evidence of a complex (but no less unacceptable) form of disablism, defined as those practices of contemporary society that exclude, eradicate, and oppress people with sensory, physical, or intellectual impairments" (Scully 2020 online, p2). The paper identifies three underlying disablist assumptions about disability, namely: overall health status, quality of life, and social utility. In relation to health status, for example, it notes that some triage protocols "appear to rely on the assumption that disability necessarily goes hand-in-hand with compromised health. In fact disability per se often has no overall health impact. ... What makes the ethical terrain here more complicated is that some disabling conditions do involve health issues that are relevant to recovery from COVID-19. ... Nevertheless, the amount of individual variation means that global categorizations based purely on diagnostic labels can easily create injustice" (Scully 2020, online, p2). Distinguishing between the general and the individual is vital, "especially since bioethics and medical ethics both have dismal track records for oversimplifying the theoretical and experiential diversity hidden under the label of disability" (Scully 2020, online, p2).

In their analysis of disability, communication and the COVID-19 pandemic, Gerard Goggin and Katie Ellis wrote that the time of the pandemic represented "a new phase in the profound disablism that is woven into the foundations of what humans think life is, and who should live" (Goggin and Ellis 2020, p.174). They argue that the treatment of disability in the pandemic had revealed the "biopolitics of disability" (invoking the account by Mitchell and Snyder (2015)), which undermines "the prospects for securing health and well-being and further degrades social equality and participation" (Goggin and Ellis 2020, 174). They concluded: "Not to put too fine a point on it, recrudescent and repugnant disablism underpinned conceptualisation, affect, plans, and practices for who would be cared for; especially in the extreme situations where medical resources ran out such as the scarce yet indispensable Personal Protective Equipment (PPE, an acronym etched in our hearts) and the totemic ventilator. ... we find out, courtesy of disability, truths about our societies and who and what matters, after all" (Goggin and Ellis 2020, 175).

#### 8.11 Conclusion

Based in prejudiced and inconsistent accounts of a good and valuable life, the Nazi crimes of the *Krankenmorde* first aimed to prevent the lives of those who might be

<sup>&</sup>lt;sup>5</sup> Scully notes that the relevant focus of the paper's discussion is disablism, rather than ableism: "Disablism is often discussed in conjunction with ableism. In disablism, the focus is on the exclusion of certain kinds of body; in ableism, focus is turned onto the kinds of body that society values and promotes" and refers readers to the work of (Goodley 2014).

born with hereditary illness or disability (or some other characteristics also deemed socially undesirable), and then expanded those aims to "euthanize" those people living lives deemed unworthy of life. Between 1933 and 1945 almost 300,000 people with illness and disabilities were murdered and 360,000 sterilized by doctors, nurses and health bureaucrats of the Nazi regime, using brutal and violent methods.

Historical, legal and political delays and obfuscation to the acknowledgement of these crimes and this group of victims has been paralleled in bioethics. As a result, the breadth of the *Krankenmorde* crimes and its victims, its relationship to the Holocaust and its contemporary significance—to bioethics and society more broadly—is less recognized or understood than other Nazi medical crimes, such as the infamous experiments on prisoners. Despite the limitations of much of the documentary sources— often medical or perpetrator records and all presented in the context of our contemporary values and discourses—we have sought here to draw attention to the lives of *Krankenmorde* victims, historically overlooked and marginalized.

We agree with arguments that bioethics theory and practice has much to gain from better engagement with this history (and with disability studies, human rights, and memory studies) not the least of which is to challenge the ableism that continues to dominate bioethical debates that affect the rights of people with disabilities. Contemporary bioethical and disability issues related to the allocation of health resources provide important opportunities to reconsider the ongoing lessons of the *Krankenmorde* and the work of bioethics.

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