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# From Eugenic Euthanasia to Habilitation of “Disabled” Children: Andreas Rett’s Contribution

Gabriel M. Ronen, MD, MSc, Brandon Meaney, MD, Bernard Dan, MD, PhD, Fritz Zimprich, MD, PhD, Walter Stögmann, MD, and Wolfgang Neugebauer, PhD

Although the name of Andreas Rett is familiar to many from his eponymous neurogenetic syndrome, his other achievements involving the care of disabled children deserve special attention. His tireless advocacy helped to bring fundamental changes in the medical and societal attitude toward disabled individuals in a city that had recently seen more than 7500 disabled children and inmates of psychiatric hospitals actively euthanized by National Socialist (Nazi) decree. Most notably, this study demonstrates the remarkable changes that can be achieved single-handedly by a vocal and energetic

physician. Yet at the same time, several instances are recorded in which Rett appeared to prioritize his own professional advancement at the expense of truthful disclosure of his own past, as well as that of some of his close associates. Dr Rett’s professional life and contributions, now 10 years after his death, presents a compelling object lesson for neurologists and others involved in the care of the disabled.

**Keywords:** eugenics; forced sterilization; euthanasia; Nazi; disability; rehabilitation; Rett syndrome

Andreas Rett’s name is familiar to child neurologists and developmental pediatricians as the eponym of an X-linked neurogenetic condition. Rett syndrome typically affects girls and is characterized by early neurodevelopmental regression leading to absence of speech, loss of purposeful manipulative skills, and of, albeit temporary, autistic features. Rett’s original description of 8 girls was published in German in 1966.<sup>1</sup> It went practically unnoticed until the report was confirmed and highlighted in the international literature 17 years later.<sup>2</sup> In the intervening years Rett continued to engage in clinical

and research activities related to this condition; however, it was not until the mid-1980s that the clinical entity of Rett Syndrome became central to his professional life.

Andreas Rett dedicated much time and energy to the management of children with neurodevelopmental disabilities. His outspoken advocacy helped to bring about fundamental changes in the medical and societal attitude toward children with disabilities in Vienna—a city which had enthusiastically hailed National Socialist (Nazi) policies after the “Anschluss” in 1938.

In this article, we examine Andreas Rett’s contributions to the treatment of children with neurodevelopmental disabilities, particularly his pioneering efforts for habilitation services. To understand Rett’s achievements within their historical context, we present first a brief overview of the societal and medical attitude toward children with disabilities in western culture since the 18th century, including the emergence and influence of race hygiene theories, their relationship with nazism, and the role that neurologists and psychiatrists played in designing and carrying out “active euthanasia” programs for children with neurodevelopmental disabilities in Vienna before and during World War II. We then present the life of Andreas Rett, focusing on its intersection with key events in political and medical history. A thoughtful consideration of the arc of his professional life within its historical context, from joining the Nazi party in his youth to his later involvement in setting up an interdisciplinary, holistic approach to childhood

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disabilities, leads ultimately to conclusions that have present-day relevance for health care professionals. Prominent among these conclusions are the social and ethical responsibilities of physicians in advocating for persons with disabilities; a reminder that health professionals are not immune to political pressure and personal ambition; and that they must therefore remain vigilant for threats to the disabled population by state, religion, science, and commercial or economic interests.

## Methods

We conducted a literature search on the history of children with neurodevelopmental disabilities and examined documents relevant to Andreas Rett and his associates provided by the Rett family and the Documentation Archives of the Austrian Resistance Dokumentationsarchiv des Österreichischen Widerstandes (DÖW). We also interviewed his widow Dr Jutta Rett and his daughter Barbara; Dr H. Krisper, a long-time associate; Dr E. Berger, Rett's successor as head of the habilitation center; Dr B. Olsson, a neuropsychologist research associate; Dr E. Gabriel, a neuropsychiatrist and recently retired head of the infamous World War II Am Steinhof psychiatric institution. The Viennese contemporary historians Dr Claudia Spring, Dr Eveline List, Dr Herwig Czech, and Mag. Peter Schwarz provided us with valuable additional information.

## Brief Historical Overview of Modern Attitudes Toward "Disabled" Children

### Approaches to Disabled Children in Western Civilization

The concept of habilitation of disabled and mentally retarded individuals does not appear with any prominence in early historical accounts. There was no organized approach, or unifying philosophy, to their care. Habilitation—from Latin "habilitas" meaning "ability"—refers to the process of assisting disabled individuals to acquire sufficient physical, mental, and social skills to allow them to cope more effectively, and possibly independently, with the demands of daily life. It was not until the early 18th century, amidst the numerous social innovations and increases in societal complexity enabled by the industrial revolution, that programs and institutions dedicated to the habilitation of children with disabilities were first seen.

Pioneers in habilitation<sup>3</sup> included Dr Jacob Rodrigues Pereira (1715-1780) who worked to design a simplified sign language for deaf-mutes. The earliest homes for habilitation of disabled children focused on the treatment of musculoskeletal problems, leading to the origins of the term "orthopedic" (literally, "straight child"). Jean-André Venel (1740-1791) established the first known hospital for

the treatment of crippled children's skeletal deformities at Orbe, Switzerland.<sup>4</sup> Early attempts at intellectual and behavioral habilitation included the efforts by Dr Jean Marc Gaspard Itard (1775-1838, who also described what later became known as Tourette's syndrome<sup>5</sup>) to educate a "savage" retarded child who was found in the woods (le sauvage de l'Aveyron). He reported some success in improving the child's social skills over a 5-year period. Dr Johann Jakob Guggenbühl (1816-1863) opened a home to cure "cretins and feeble-minded" children in Abendberg, Switzerland. He espoused the concepts of good diet, physical exercise, sensory stimulation, speech training, and motivation (dietary iodine supplementation was introduced only in the early 20th century). Dr Edouard Onesimus Seguin (1812-1880) used training methods to improve idiocy at the Hospice des Incurables and at the Bicêtre close to Paris. Dr Samuel Gridley Howe (1801-1876), director of the Perkins Institution for the Blind in Boston, was deeply impressed with the training of "blind children who were also idiotic."<sup>3</sup> He published his text *On the Causes of Idiocy* in 1858,<sup>6</sup> and argued among his contemporaries that the training and education of the feeble-minded was a public responsibility. The first medical journal dedicated to mental retardation was published by Rösch in Germany in 1850, and subsequently William Wotherspoon Ireland published his advanced text *On Idiocy and Imbecility* in 1877.<sup>7</sup> These pioneering achievements served as models for similar work evolving across Europe and North America.

As organized clinical study in the field grew, it gradually became apparent that retardation could not be "cured" through intensive training of cognitive functions and that amelioration, rather than normalcy, was a more reasonable goal. By the 1870s many of the residential institutions for children with disabilities had grown to the point that they were giving shelter to hundreds of children. These facilities were unable to provide individual care and were verging toward becoming general "asylums for the incurable." The solution was therefore to subdivide these institutions according to the children's abilities into a "school proper," an "industrial section," and an "asylum." These homes and asylums provided education, workshops, and nursing care. Most were run by philanthropic or clerical groups, and only later by the state or community.

However the end of the 19th century was a time of changing societal attitudes toward the retarded population. With the growth of residential care came a shifting away from the humanitarian habilitative approach, and in its place a growing sentiment that society should protect itself by segregating such "undesirable elements, spreaders of poverty, degeneracy, crime, and disease."<sup>8</sup>

### Toward Eugenics and Racial Hygiene

The late 19th century saw Darwin's theory of natural selection, controversial in its own right, borrowed and

tentatively applied to the workings of human society. New terms that were introduced included "eugenics" by Sir Francis Galton (1822-1911), who was a half cousin of Charles Darwin; "social Darwinism" by Herbert Spencer (1820-1903); and "Rassenhygiene" (racial hygiene) by Alfred Plötz (1860-1940).

Advocates of these related concepts viewed social institutions such as welfare and insane asylums as inappropriate because they would in effect cancel out the inherent disadvantage of "inferior" humans, allowing them to survive and reproduce at competitive or faster levels as compared with the "superior" humans that made up respectable society. Supporters contended that society would be awash with "inferiors" if corrections were not applied quickly. These movements gave much thought to means of reducing the numbers of mentally retarded, primarily through segregation of sexes and sterilization. In all cases of ensuing sterilization statutes the mentally retarded were lumped together with psychotics, psychopaths, and criminals.<sup>3</sup>

By the turn of the century the consensus in North America was also that life-long segregation was the best policy for dealing with the retarded population. Dr Walter Elmore Fernald (1859-1924), superintendent of the "Massachusetts School for Idiotic Children" and a leading advocate of eugenics, stated (1912) that "the mental defectives in our penal institutions should be recognized and transferred to permanent custody in suitable institutions and farm colonies."<sup>9</sup> Later, Fernald adopted a policy of sending patients back to the community. In 1919 he published a survey on the social outcome of persons discharged over a 25-year period from the Waverly Institution for the Retarded in Massachusetts. Contrary to the accepted theories, the study results showed that "many unpromising cases did well."<sup>10</sup> Although this study helped contribute to a better understanding of the social possibilities for this population and furthered their gradual integration in North American society, other thought leaders in the field, including the renowned neurologists Foster Kennedy (1884-1952) and William Lennox (1884-1960), continued to actively champion the eugenic movement in North America during and after World War II.<sup>11</sup>

Genuine scientific concepts and research on mental retardation were seldom seen in the medical literature, as if this population did not exist. The German neuropsychiatrist Wilhelm Griesinger (1817-1868) was an exception, believing in integration of the disabled in society.

### Evolution of the Race Hygiene Concept

During the first years of the 20th century, a vast transformation in the scientific concepts of human heredity began to emerge, triggered by the views of German biologist August Weismann that individual heredity was permanent, and by the rediscovery of Austrian monk Gregor

Mendel's work on the transmission of specific traits. Though insufficient to fully explain the early 20th century eugenic concepts of heredity, these scientific observations were key components in their formulation. To appreciate this scientific transformation, it is essential to understand that before this century a trait could be described as "hereditary" without necessarily implying that it was permanent. Weismann's conceptual reframing suggested that treatment of individuals with inherited diseases would provide no benefit to their offspring. It was selective control of reproduction, not environmental improvement, that offered the only means of improving heredity. Because individual heredity was permanent, any improvement produced by eugenic selection would be permanent as well. For Weismann, once a trait had been eradicated it would stay eradicated. It was only with the acceptance of Weismann's view of heredity that supporters of eugenics became able to discuss the promise of "final solutions."<sup>12</sup>

The concept of Rassenhygiene appealed to increasing segments of the German and Austrian scientific community from before World War I through the 1920s and 1930s. The overwhelming majority of the medical profession, led by neurologists and psychiatrists (the neuropsychiatric discipline in Vienna was only separated in 1971), anthropologists (eg, Eugen Fischer, 1874-1967, and Otto Reche, 1879-1966), and biologists, played an instrumental role in generating, legitimizing, and popularizing the anthropological theories of the time. This, in turn, exerted a major reciprocal influence on the scientific concepts underlying those fields. National Socialistic ideology was perfectly in accord with Rassenhygiene, and when the Nazis came to power many of these university-based medical scientists participated as "experts" in elaborating and implementing the derived policies of forced sterilization of individuals with suspected neuropsychiatric hereditary disorders.

In its earliest form, the specific concept of Rassenhygiene was concerned primarily with the declining birthrate in the German state and the increasing number of mentally ill and disabled in state institutions. It was only later that the "Jewish question" and "de-nordification" would come to dominate this ideology in Germany and Austria.

### The Role of Neurologists and Psychiatrists in Vienna, Austria

More than any other professional group, neuropsychiatrists were deeply involved in the Nazi medical crimes of forced sterilization (Figure 1), killings, and human experimentation. They served as scientific and ideological forerunners, as political advisors, consultants, institutional directors, responsible health-policy makers, and health officials, and as exclusive exterminators in the euthanasia institutions.<sup>13</sup>





Figure 1. Nazi newspaper “Völkischer Beobachter” (the official organ of the NSDAP) proclaiming and promoting the law of forced sterilization for individuals with hereditary conditions in the former Austria.<sup>25</sup>

The prominent neuropsychiatrist Erwin Stransky (1878-1962) was an early Austrian advocate of racial hygiene concepts who stated in his published work that the psychiatrist is the safest guide to educate and lead the courts “in the sense of a medical imperialism which is the imperialism of culture.”<sup>14</sup>

The eminent Julius Wagner-Jauregg (1857-1940), known for being the first neuropsychiatrist to receive the Nobel Prize (1927), was also a strong proponent of racial hygiene and an applicant for membership in the Nazi Party (NSDAP). In 1935 he supported the Nazi law mandating forced sterilization and criticized the Austrian government at the time for rejecting the policy of racial hygiene. Wagner-Jauregg stated that people with mental diseases or criminal genes were “individuals who, because of lasting genetic mental defects, are a danger to the community and unable to fit in.”<sup>15</sup>

Rett’s mentor and friend Walter Birkmayer (1910-1996), known for his 1961 work demonstrating the therapeutic effect of L-dopa replacement in patients with Parkinson’s disease, was also a radical activist in the Nazi Party and the Schutzstaffel (SS), and chief of the racial political department of the NSDAP in Vienna. In 1938 he said the following at an evening seminar for doctors of the SS-section “Donau” about heredity of neurological diseases: “The privilege remained with our nation to spawn a genius, who instinctively recognized and demanded that only the purity of our race and the health of our genes can save our people from decadence. And it is our duty as fanatic followers to exterminate everything that is morbid, impure, and corruptive.”<sup>16</sup> In 1939 Birkmayer was forced to resign from the NSDAP and the SS because of his “non-Aryan” descent. In a medical legal document from October 8, 1944, he commented that “Every epileptic and in a wider perspective

every criminal have defects in their personalities. They need to be institutionalized [which was de facto a death sentence under Nazi regime] otherwise every person with brain injury or epilepsy would be able to commit criminal activities without being prosecuted."<sup>17</sup> In 1964 Birkmayer admitted to having made a "mistake," but still advocated for sterilization of people with hereditary diseases, though on a voluntary basis.

### Toward Systematic Extermination of Disabled Children in Vienna

The decision to kill all mentally and physically disabled people had allegedly been formalized in Nazi doctrine as early as 1935.<sup>18</sup> However it was not enacted until 1939, the year of the outbreak of World War II, under the pretext that it was deemed necessary to make space for wounded soldiers, to free health care professionals to tend the wounded, and to save medicine and food.

The program of forced sterilization of disabled people had been under way in Germany for several years prior to this, and over 400 000 such procedures took place there from 1935 to 1939. By contrast Austria, whose population made up 8% of the greater German Reich, recorded only 6000 forced sterilizations beginning in 1938. From 1939 onward, forced sterilization was increasingly replaced by the euthanasia murder operation, with at least 25 000 Austrians with various health ailments becoming victims of Nazi euthanasia.<sup>19</sup>

From August 1939 the interior ministry ordered physicians and midwives to report all cases of newborns with severe disabilities. Initially those to be reported were "all children under three years of age in whom any of the following serious hereditary diseases were suspected: idiocy and mongolism, particularly those with blindness and deafness; microcephaly; hydrocephaly; malformations of all kind mainly of limbs, head and spine; and paralysis." A panel of three medical experts in Berlin then assessed the reports before giving their approval for the extermination. The extermination in Vienna took place at Am Spiegelgrund, the child and adolescent neurological and behavioral pavilions, where 789 children were documented to have died, as well as at the neighboring psychiatric hospital Am Steinhof, where at least another 187 children perished.<sup>20,21</sup> The psychologist and psychoanalyst Dr Igor Caruso (1914-1981) and the child psychologist Dr Edeltrud Baar (1910-1958) provided expert opinion and guidance, based on their personal evaluations of disabled children using standardized tests, on the decisions regarding whether specific children were candidates for extermination or sterilization.<sup>22</sup>

The children were often murdered by a combination of starvation, exposure to cold, and barbiturates. Their deaths were usually recorded as "pneumonia."<sup>23</sup> Many children with neurodevelopmental disabilities underwent

"investigation" with pneumoencephalography or spinal taps only days prior to their demise. Three inmates of the children's home Am Spiegelgrund, Friedrich Zawrel, Alois Kaufmann, and Johann Gross, who survived, were later able to provide eyewitness accounts of some of the atrocities. Key physicians in the killings perpetrated at Am Spiegelgrund were Drs Hans Bertha, Erwin Jekelius, Ernst Illing, Margarethe Hübsch, Marianne Türk, and Heinrich Gross.<sup>24</sup> Under the instrumental direction of the physicians at these institutions, autopsies were almost always performed and the brain and other organs were kept for medical research.<sup>25,26</sup> Ernst Illing researched the pathologic anatomic correlations with pneumoencephalographies in patients with tuberous sclerosis.<sup>27</sup> Dr Elmar Türk, brother of Marianne Türk, experimented with tuberculosis vaccine on disabled children, infecting them later with the active bacillus. He kept the children at the university children's hospital for an observational period and then sent them back to Am Spiegelgrund to perish and have their autopsies performed.<sup>28,29</sup>

### Postwar Climate in Vienna

After the war a denazification law to purge the Austrian state and society from Nazis was enacted but not subsequently applied. The antifascistic period in Austria rapidly dissipated from 1947 onward. It was characterized by leniency and amnesty toward crimes against humanity and reintegration of the former Nazis into the mainstream of society and academia.<sup>21</sup> After 1950, many physicians who had indisputably committed atrocities were reinstated.<sup>30</sup> The question of how Nazi medical practices had provided science with an abundance of experimental findings on human subjects was only marginally addressed.<sup>31</sup>

Eduard Pernkopf, the former Nazi dean of the medical school (1938-1943) and "Rektor Magnificus" (President) of the University of Vienna (1943-1945), was imprisoned for 2 years. However, Pernkopf was later permitted to finish his hand-drawn anatomic atlas, which used as models the bodies of 1377 persons executed in Vienna as victims of the Nazi judicial system.<sup>32</sup>

Hans Bertha, the euthanasia mass murderer from Am Steinhof, became professor of psychiatry and dean of the medical faculty of the University of Graz. Erwin Jekelius, head of the Am Spiegelgrund, died in a Russian prison. His successor Ernst Illing was hanged following his trial by the Viennese People's Court in 1946. Marianne Türk was sentenced to 10 years but was released after 2 years and was professionally rehabilitated in 1952. Margarethe Hübsch was acquitted. The perpetrators of forced sterilization and "operation T4" (named after Tiergartenstrasse 4, the address of the Berlin Chancellery offices where the program to exterminate disabled persons was headquartered) in Vienna were not indicted.<sup>21</sup>

Gross had been captured and incarcerated by the Soviet army in 1945. In 1948 he was apprehended by the authorities in Vienna and charged with the murder of children at Am Spiegelgrund.<sup>24</sup> Gross was prosecuted under the German penal code which held (at the time) that the definition of murder did not apply in the case of mentally handicapped persons, as such persons were not capable of reasoning. Gross was found guilty, not of the murder of the children, but of manslaughter. The case was appealed to the supreme court, which suspended the verdict and referred the case back to the original court. The prosecutor, for unknown reason, withdrew the indictment against Gross, and in May 1951 the case was closed.

In 1952 Gross started publishing his "research" on the brains of the active euthanasia victims, including work in collaboration with Andreas Rett and Kurt Jellinger.<sup>33,34</sup> In 1958 he became a renowned expert in forensic neurology and psychiatry on Stransky's recommendation. He was promoted to head of a department at Am Steinhof in 1962, and in 1968 became director of the newly established Boltzmann research institute for malformations of the nervous system.<sup>21</sup> He was awarded the Honorary Cross for Science and Arts First Order in 1975.

In 1976 Gross was confronted by his former victim Friedrich Zawrel, who exposed his role in the killings of the children at Am Spiegelgrund. In 1999, after new evidence had been found, Gross was charged with murder by the Viennese District Court, but the procedure was soon interrupted as Gross, aged 84, was suffering from dementia.

Walter Birkmayer, like Gross and other Nazis, took advantage of the established Social Democratic party and its academic circles to advance professionally.<sup>17</sup> In 1954 he became director of the neurological department at the Lainz hospital, where Rett trained for 6 months. Following Birkmayer's discoveries on L-dopa he was promoted in 1963 to professor, and in 1968 became head of the Boltzmann Research Institute in Neurochemistry for his research on Parkinson's disease. The Austrian Parkinson's Society continues to bestow regularly the Birkmayer research award.

Dr Kurt Jellinger may exemplify post-World War II medical academic reality in Vienna. Jellinger and Gross became codirectors of the Boltzmann Institute for Research in brain malformations in 1968. Together they published at least seven scientific papers from the pathological material of the active euthanasia victims.<sup>33-41</sup> Jellinger took over the directorship when Gross was forced to resign in 1989. Shortly afterward he tried to mislead the Pernkopf committee investigating the origin of the pathological specimens, claiming that only a few preparations in the laboratory belonged to exterminated patients, where in fact over 400 formalin preparations and thousands of microscopic slides from the victims were found with their medical histories systematically filed, when the laboratory

was shut down. Ironically, the Springer Publishing House has been awarding the Kurt Jellinger Prize for Outstanding Scientific Writing in Neuropathology.

Amidst this climate of leniency and reintegration of former Nazis, and well into the 1960s and 1970s, societal awareness and support of persons with developmental disabilities in Austria was virtually nonexistent. Parents of children with neurodevelopmental disabilities received neither state or community help nor proper medical assistance. Children with disabilities lived in isolation, often hidden by families who remained frightened of existing prejudice and the persisting terror of the Nazi period. Others were nursed and kept isolated in institutions without any specific therapy. This was the societal and medical academic climate in which Rett's professional development, and his later contributions, evolved.

## Andreas Rett: His Life and Accomplishments

### Rett's Early Life and Medical Training

Andreas Rett (1924-1997) was born in Fürth, Bavaria. For economic reasons his family moved in 1929 to Innsbruck, Austria, where his father opened a prosperous dry-cleaning and dyeing factory. Andreas Rett's emerging political views in his youth were imprinted by the dominant Nazi philosophy. On September 1, 1942, at the age of 18, he joined the Nazi Party in Innsbruck (no. 9260108), a fact he never disclosed to his family.<sup>17</sup> Rett also disobeyed his father by choosing to study medicine. The senior Rett had intended his son to follow him in the family dry cleaning business. When Andreas refused, his father disinherited him and groomed his younger brother to take over the family establishment.

After only two semesters in medical school, Andreas Rett was recruited to join the German navy, where he served for the next 3½ years. He was wounded twice, and subsequently served on a hospital ship in the Mediterranean where, despite his inexperience, he was professionally engaged as a clinician and surgeon. He later recalled: "If we students did not do the work then nobody did it because there were not enough trained doctors available."<sup>42</sup>

After the war, Rett returned to Innsbruck with the intention of completing his medical studies. However, he was initially denied reentry into the university because of his past affiliations, and more importantly because of his active and enthusiastic involvement in a leadership position within the Hitler-Jugend (Hitler Youth).

Rett responded in a letter in which he denied any such involvement, categorically stating that he was never in any leadership position in the Hitler Youth and had never applied or joined the NSDAP. Such written statements were necessary and not uncommon for former Nazi party members wishing to reestablish their professional lives in

postwar Austria. The university accepted Rett's statement and he was readmitted and allowed to continue his medical studies. Following graduation in 1949 he moved to Vienna to train in pediatrics (1950-1954) at the private Preyer's hospital for children under the direction of Konrad Eberle.

### **Rett's Involvement with Children with Neurodevelopmental Disabilities**

One of the first patients with neurological problems Rett ever encountered was Franzi, a girl with epilepsy. Rett noted that she showed an increased eosinophil count prior to every seizure. This unusual observation led him to approach Walter Birkmayer and later Hans Zellweger in Zurich to understand this phenomenon. Their ensuing discussions formed the basis for Rett's first neurological scientific paper in 1952.<sup>43</sup> His interest in that particular case was in retrospect the beginning of what would become the focus of his medical career, as well as a personal devotion to improving the predicament of children with neurodevelopmental disabilities.<sup>44</sup>

During his training Rett recognized the lack of continuity of care for patients with chronic neurodevelopmental disabilities. As a result of his early scientific publication, patients with neurodevelopmental disorders were being transferred to the ward he was working on, where he increasingly felt a sense of responsibility for children with disabilities. He therefore opened a follow-up outpatient facility. There he learned firsthand about the importance of long-lasting supervision, parental concerns, and problems at school and within the family. He later recalled, "I opened an outpatient clinic one afternoon per week that expanded rapidly. One day the professor [Konrad Eberle, who incidentally was not a Nazi] came down and saw about 20 children waiting. He then shouted: 'These idiots are a disgrace to my hospital, leave this place with these "mentals," I don't want to see you any longer.'"<sup>42</sup>

### **Origins of the First Habilitation Center for Children with Neurodevelopmental Disabilities in Vienna**

At this time in Vienna, political connections, promotions, and support were most efficiently cultivated in unofficial male societies that were often affiliated with political parties. Andreas Rett was initiated as a freemason and entered the social democratic party and its alliance of social democratic academics, as well as the "socialist democratic physician circle," named after the surgeon Felix Mandl. Rett was able to enlist the support of various members of these social organizations, including Franz Jonas, the mayor of Vienna, in his quest to create a home for children with disabilities. Rett used the recently evacuated pavilion XVII of the Lainz old-age home, built in 1899, for his facility. The children's home was opened

on January 2, 1956, with 2 physicians and 12 nurses. Soon 85 children were brought in from nursing facilities in old-aged homes and psychiatric asylums like the Am Steinhof, and before long another 200 were on a waiting list. With Rett as the director of this special care unit, it quickly evolved from a nursing home into the first genuine habilitation center for children with neurodevelopmental disabilities.

Rett's pioneering achievements included in-house interdisciplinary collaboration between medicine, psychology, remedial educators, and various allied therapists, as well as social work and parent lay society. Laboratories for chemistry and cytogenetics were also included within the institution. He observed that "disability work means collaborative work," a sentiment which was in sharp contrast to the practice of most specialists at the time, who tended to extend their professional interaction only to others of their own discipline.

Based on the concept that hearing was the last preserved sensory capacity of a dying person, he believed that persons with disabilities could be therapeutically reached through music. In the late 1950s he began to incorporate both occupational and music therapy in his habilitative programs. Shortly thereafter he traveled to London to meet Berta and Karel Bobath and to learn about their newly developed stimulation program for persons with spasticity, which he introduced in Vienna on his return.

Through his clinical experience with children with disabilities and their families, Rett came to recognize the importance of continuing care and communication, which he believed should be applied continually throughout life, "from the crib to the grave," rather than arbitrarily disrupted around the age of 19 years.<sup>44</sup>

As the reputation of Rett's new institute, and indeed of Rett himself, began to grow within Vienna and the surrounding regions, greater numbers of children with neurodevelopmental disabilities were brought to see Rett by parents seeking consultation and habilitative therapy. Despite skepticism by the medical establishment, the institute continued to expand. To meet the demand, Rett brought on additional nurses, physicians, and psychologists, including the first "clinical psychologists" ever recruited in Vienna. The first electroencephalography (EEG) machine (1 of 3 in Vienna) was also donated to the institution early on. However, it soon became apparent that this 1899-built edifice had an inappropriate layout, insufficient space, and unacceptable sanitary conditions to continue to house this growing program.

### **Development of a Truly Integrated Multidisciplinary Habilitation Institute for Children with Neurodevelopmental Disabilities**

In a document prepared on December 9, 1958, Rett detailed conceptual plans for a new facility for disabled



children. He was acutely aware, based on his past clinical experiences, that a large proportion of children with disabilities in the region could not be looked after effectively by their families any longer, yet had too high cognitive abilities to be integrated into traditional nursing homes. He strongly believed that optimal care should be available to every member of society, irrespective of disability. He also subscribed to the philosophy that the worth of a society is measured by its level of care for the weakest segment of its population. With this background and mindset, he sketched his vision for a new institute.

He proposed an in-house program of intensive educational and medical habilitation that could extend over several years until these children could be fully integrated in society. The institution needed to be able to provide the following requirements: (1) an optimal surrogate family for the patient; (2) holistic and intensive remedial-therapy and medical care; (3) the ability to undertake investigation into the underlying causes of prenatal or perinatal brain injury to enable future prevention. Asperger's work in remedial education was a source of inspiration for Andreas Rett in these planning stages. It was his hope that with proper medical and pedagogic intervention, these children would eventually be able to access and benefit from special education programs, possibly normal schooling, and hopefully return to their family environment.

However, there were no actual institutions in Vienna that could easily adapt to this plan at the time. Therefore, he met with multiple hurdles before bringing such an institution to fruition.

In 1963 the mayor of Vienna visited Rett's clinic. He concluded that a new building was required. Rett was allowed to choose the architect, Anton Schweighofer, with whom he would work closely on the design. In 1975 this modern facility, the first of its kind in Europe, was inaugurated (Figure 2). It contained both inpatient and outpatient facilities, including 101 beds and accommodating 200 to 350 outpatient visits per week, a kindergarten, school, nursery, therapy facilities, and play areas. Within a single day new patients would be interviewed by clinicians and social workers, have a neurological exam, psychological testing, audiometry, EEG, and blood tests, leading to the formulation of a working diagnosis and a management plan. In addition, persons with disabilities often found employment within the institution.<sup>44</sup> The facility was run "like a big family" with Rett at the top in the role of patriarch, making almost all decisions.

As the years passed, problems began to arise when some of the severely disabled children under the institute's care grew into adults. By the late 1980s some of these adults were, for want of better arrangements, kept in large fenced cribs that were bolted to the walls to prevent the cribs from moving. There was no adult psychiatric expertise in the facility to deal effectively with the behavioral disorders of these patients. Over time Andreas Rett gradually decreased

his involvement with these ward patients, turning over the responsibility for inpatient management to his coworker Dr Krisper, while he became more engaged with an international clinic for patients with Rett syndrome.

Seen through the lens of history, Rett's establishment of multileveled constructive and effective care for children with neurodevelopmental disabilities represented his crowning professional achievement. It represented the product of not only his energetic advocacy on behalf of this disadvantaged population, but also his apparently intuitive understanding of the need to incorporate various specific features including: (1) political advocacy at the highest level, (2) community education regarding attitudes toward disabilities and retardation, (3) dedicated facilities adapted to the medical and educational needs of children with disabilities, (4) multidisciplinary care, with close collaboration between disciplines, (5) ongoing professional education, (6) creation and leadership of well-organized and effective parent support groups, and (7) research backed by long-term guaranteed funding. It is remarkable that Andreas Rett achieved what he did, virtually single-handedly, in the midst of a culture dominated by professional opposition and little sympathy for any effort to support the care of these children, all within the 2 decades following the worst state-sponsored atrocities ever committed toward these children.

### Andreas Rett on Remedial Education

Rett strongly believed that retarded children had cognitive potential that could be unlocked through remedial education, or "Heilpaedagogik" in German (which translates to "curative education").<sup>45</sup> He referred to the successes in the early treatment of deaf and blind children, but realized that remedial education of globally disabled children would be even more challenging. He believed in integration as a goal, but not at all costs. In Rett's opinion, integration could be successful only if (1) the child is prepared physically, cognitively, and emotionally, and (2) the school is ready, from the leadership down to the teaching staff and the rest of the students. He favored differential and individualized remedial education for students with specific brain dysfunction, tailored to their needs and condition. Rett, in collaboration with the "Lebenshilfe" advocacy society, opened sheltered work environments for youth and adults with neurodevelopmental disabilities.

### The Discovery of the Rett Syndrome

One afternoon in 1965 Andreas Rett noticed two girls in his waiting room, each mentally retarded, each sitting on her mother's lap. He noticed that both of the mothers were holding the arms of their daughters, gently restraining them. What caught his eye was that, as both mothers released the grip on their daughter's arm simultaneously,



Figure 2. Andreas Rett in front of the newly opened habilitation center in Vienna.

both girls began to make the same unusual but rather stereotyped hand movements. He asked the mothers to hold and release their daughters' arms repeatedly, which resulted in the same movements. Rett decided to look into the situation further, and recognized that these girls had strikingly similar clinical and developmental histories.

After discussing these observations with his nurse Martha, and thanks to a well-organized filing system, Rett was able to identify an additional six girls with the same clinical and developmental features. He arranged for all these girls to attend the clinic and to sit next to each other. They engaged in repetitive hand washing movements without looking at each other. He concluded that he was observing a previously unrecognized syndrome.

It is a prime example of discovery coming to the prepared mind. Rett's immense clinical experience permitted

him to recognize that the girls' movements and attitudes differed from the other types of stereotypic movements so often displayed by handicapped children.<sup>46</sup>

In the initial cases, blood ammonia levels were reported as increased; however, this finding was not replicated later. Chromosomal and other metabolic work-up revealed only "non-specific cerebral atrophy."<sup>47</sup> One year later Rett published a report on 22 cases through a small Austrian publishing house.<sup>47</sup> He also presented a film to the medical society in Vienna but was told rather dismissively that this condition was already known to exist.

Rett's descriptions of this syndrome generated virtually no interest or discussion over the next 15 years, despite his collection over that time of 50 cases from Austria and elsewhere. However by 1984, when Rett attended the first international workshop at the Kennedy Institute in

Baltimore to present his data, there were more than 100 other researchers and clinicians there to present their experiences with over 600 patients.<sup>46</sup>

There were three reasons felt to be chiefly responsible for the delay in awareness of the syndrome: (1) difficulty in conveying the characteristics of a movement disorder in writing; (2) reluctance in accepting a constellation of clinical features as a specific syndrome when there is no laboratory marker; (3) failure to attract wider attention because of poor linguistic skills and the "hierarchy" of publications wherein attention is focused mainly on selected journals.<sup>46</sup> Rett himself added "a typical Austrian misfortune" as another reason.

Rett also noted and reported the syndrome of benign familial neonatal convulsions in a 1964 article but never referred back to this publication.<sup>48,49</sup>

### Andreas Rett's Views on Sexuality and Sterilization

Rett believed that individuals with retardation were unable to handle intimate sexual relationships properly. It is unclear whether his opinion was based on indiscrete observations in his institution or not. Rett was convinced that most individuals with retardation lacked the necessary reason, insight, conduct, ethical maturity, and responsibility to engage in meaningful and lasting sexual relationships. Sexuality, he believed, should be linked to responsibility. Individuals needed to know how to control their sexual drive, and he felt that the mentally disabled would be overburdened with it. He criticized the Lebenshilfe organization for distributing leaflets describing how to use condoms and how to conduct sexual intercourse with no reference to building up partnership. He resigned as president of this organization and had heated debates about these issues with health professionals, parents, and his own daughter. Rett insisted that he was keeping morality out of the discussion.<sup>50,51</sup>

Andreas Rett's support and encouragement of parental consented sterilization of their retarded daughters was already controversial at the time. His beliefs were not related to political racial ideology but rather were based on his intention to protect retarded women from unwanted pregnancies.

### Rett, the Nazis, and "Scientific" Publication on Brains of Euthanasia Victims

During his medical studies in postwar Innsbruck, Rett took a course on "Biology of Inheritance" which was given by Friedrich Stumpfl, a fanatic Nazi and notorious racial hygienist. Rett never made reference to this exposure later in his life.

Decades later, Seidler and Rett published two volumes on racial biology and National Socialism.<sup>52,53</sup> They commented specifically on the "racial surveys" (erb- und

rassenkundliche Untersuchungen) that were conducted during the war by the Department of Anthropology of the Viennese Museum of Natural History ("Naturhistorisches Museum"). Seidler and Rett determined that these surveys, undertaken on behalf of the Offices of Hereditary Research in Berlin and Vienna, constituted "certifications" of "racial affiliation," and therefore were tools that led to life and death decisions of Jewish people as defined by the Nuremberg Laws. More generally, they criticized Nazi policies, including forced sterilization and active euthanasia, as inhuman. At the time of publication (1982 and 1988) these books were lauded for being the first analytic studies about these topics in Austria, incorporating new sources of previously unpublished information. Later, seen in retrospect and in light of further historical perspectives, Rett's and Seidler's books were criticized for being too general and superficial in their analyses and for failing to identify the perpetrators by name.

Rett also collaborated with Heinrich Gross on an article based on the brains of euthanasia victims.<sup>33,35</sup> In their material and methods section the authors stated that the study was based on the results of microscopic study of the central nervous system in 891 cases of mental retardation and of neurological disorders occurring in early infancy and childhood. "... As in previous reports (by Gross et al.) only those necropsy cases are dealt with, in which infantile cerebral lesions had become clinically evident within the first 3 years of life, particularly through severe psychomotor retardation and/or progressive mental deficiency. In addition, our sample includes a number of brains collected from a department of paediatric neurology and from patients in whom rehabilitation or training had at one stage seemed possible" probably from Rett's unit. We assume that Rett was aware that the majority of these brains belonged to the victims of pediatric euthanasia, but he never acknowledged this particular ethical issue in public.

The three—Jellinger, Gross, and Rett—collaborated and cowrote an abstract on the pathology of 28 individuals with holoprosencephaly.<sup>34</sup> However, Rett did not appear as a coauthor in the published article,<sup>41</sup> possibly as a result of the media attention caused by the open letter by Dr Werner Vogt and associates in January 1979 accusing Gross of participation in the Nazi euthanasia atrocities perpetrated on disabled children at Am Spiegelgrund.<sup>17,24</sup>

Following the public awareness on the crimes committed by Heinrich Gross, the Social Democratic Organization for Intellectuals and Artists engaged the historians Wolfgang Neugebauer and Peter Schwarz to investigate the role played by organizations such as the social democratic party in effectively "whitewashing" former Nazis. By facilitating their admission as members, such organizations endowed former Nazis with a perception of societal respectability as well as useful social contacts, helping to pave the way for their reentry into public and academic

life. Neugebauer and Schwarz's book,<sup>17</sup> published in 2005, documented not only the early Nazi connection of Andreas Rett and Walter Birkmayer, but also their roles as organizers and de facto leaders of the party's academic physician forum (Felix Mandl Circle) during the 1960s, meaning that they were likely in control of admissions.

## So, Who Was Andreas Rett?

A complex man, Andreas Rett left a legacy of praiseworthy achievements as well as lingering questions. It remains difficult today to reconcile the dramatic contradictions inherent in his professional life. How can someone embrace the philosophy of National Socialism yet also contribute so much to advancing the humane care of children with disabilities? Perhaps his professional work represented personal opportunism in a different guise. Or perhaps he sought personal redemption or atonement for earlier opinions or actions that he later regretted.

Objectively, Rett's greatest professional achievements stemmed from his conviction that children with disabilities needed to be socially rehumanized and habilitated, believing that their brains have the capacity and plasticity to improve with proper therapy. He managed to translate his beliefs into practice despite serious obstacles, not the least of which came from the medical establishment in postwar Austria, a sizeable proportion of which had been part of the Nazi regime.

In achieving his goal—indeed perhaps as a result of the very personality traits that enabled him to be successful—Rett made himself many enemies. The animosity toward him culminated in 1980 when Rett was not elected to the presidency of the Austrian Pediatric Society after his mandate as vice president and president-elect of the society. Typically for him, he responded by resigning completely from the society.

He may also have been a victim of professional envy because he came from an academically less respected community facility yet he received more scientific recognition, published more papers, and organized more international conferences than any of the academic physicians at the prestigious university hospital. As recently as 2006, the name of Andreas Rett was conspicuously omitted by Kurt Jellinger in his review of the history of neuroscience in Vienna.<sup>54</sup>

Rett's many accomplishments, which were all the more impressive when considered within the historical context, remain somewhat tainted by present-day standards, due to the unanswered questions about his past. In the decades that followed the war, several former members of the Nazi party and Hitler Youth publicly acknowledged their past involvement and renounced the inherent political and social ideology. Rett never did so, perhaps out of concern for the effect on his professional reputation, shame, or

lack of civic courage. However, his failure to admit and renounce this aspect of his past, coupled with his postwar associations with Gross and Birkmayer, together cast a pall of suspicion regarding his personal moral philosophy, or perhaps his flexible morality in the face of opportunity.

Rett's close associates acknowledged that from the mid-1980s onward Rett appeared to spend more time building his professional reputation than engaging in cultivating habilitation programs in Vienna or elsewhere in Austria. He also neglected to foster a future generation of clinicians and medical scientists to advance his and other habilitation institutions for disabled children.

## Conclusion

Today neurologists and psychiatrists continue to be accorded a level of privileged trust within society. The manner in which that trust is used, consciously or not, can have profound and lasting effects. An examination of the life of Dr Andreas Rett provides an object lesson in this regard.

Most notably, it demonstrates the remarkable changes that can be achieved single-handedly by a vocal and energetic physician. Rett's position in society as a neurologist gave him the potential to effect change in public perception and policy, and to provide resources and care to an underprivileged population that could not advocate for itself.

Yet at the same time, several instances are readily seen in which Rett appeared to prioritize his own professional advancement at the expense of truthful disclosure of his own past, as well as that of some of his close associates.

Clearly the responsibilities of our profession extend beyond the direct clinical consultation and include wider ethical and social obligations. Advocacy regarding social equality, support of lay patient organizations, education of the public, provision of evidence-based guidance to the courts and makers of public policy, and whistle-blowing regarding neglect or abuse of the disabled populations, are all examples of our broader duties.

Even in democratic western societies health professionals are not immune to inappropriate pressures and influence, whether they relate to state, religion, science, commercial, or economic interests. Remaining vigilant against threats to the disabled, irrespective of public trends, will always be at the core of our professional responsibilities.

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