Polio, Disability, and American Public Schooling: A Historiographical Exploration

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Alas for Tiny Tim, he bore a little crutch, and had his limbs supported by an iron frame! Charles Dickens¹

Poliomyelitis, a virus that quickly attacks the central nervous system, struck the United States in 1916 with devastating results. Twenty-six states reported some 27,000 cases, claiming 6,000 deaths. Polio hit New York City the hardest, with 8,900 cases and 2,400 deaths alone. Public responses reverted to age-old quarantines, isolating the infected and those suspected of carrying the contagion. Pennsylvania state officials ordered medical inspectors to guard the roads, blocking terrified migrants attempting to escape New York City; civil authorities in Paterson, New Jersey, likewise denied entry to desperate New Yorkers. For the next forty years, communities across the continent, from the Yukon to Montgomery, Alabama, banned public gatherings to reduce the possibility of further contagion.²

The morbidity rate continued to climb during the next four decades. With 5,000 cases reported nationwide in 1933, the appearance of the baby boomers dramatically increased the tempo. In 1946 and 1953, for example, the United States alone accounted for 25,000 and 57,628 cases, respectively. Until 1955 and the introduction of the Salk vaccine, 'polio enjoyed the infamous distinction of being the only remaining serious epidemic disease in the Western world'. It proved to be especially virulent among children, ages five to nine, until the 1930s when it began to infect older children and adolescents. Poliomyelitis lurked in the shadows, a persistent threat of sudden incapacitation or even death: the reality of playing outside one sunny, warm summer day and the next fighting for survival in a frightening hospital setting, permeated with the pungent smells of alcohol, disinfectant, and ether, surrounded by strangers in starched, white uniforms, isolated from friends and family. The lives of

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healthy children, if they even survived the initial onset of the disease, experienced a transformation almost overnight: they turned into what became known as *crippled children*.

Poliomyelitis ravaged children's bodies. They lost dozens of pounds within the first couple of weeks and, in some cases, once healthy bodies became emaciated. Their flaccid bodies and sallow skin caused a skeletonlike appearance. Bowel and urinary failure led to the insertion of catheter tubes and a regimen of enemas. The virus therefore not only invaded the body, but nurses and physicians who fought it had to violate it with instruments - a loss of dignity and humiliating for a young child. They gagged on their own mucous. Bed sores and the threat of bacterial infection complicated hospitalization. By the early 1950s, when polios experienced respiratory failure, even while in an iron lung, doctors had to perform emerging tracheotomies. Polios, by way of the angled mirror mounted on the iron lung above their heads, watched in horror as frantic physicians made an incision in their throats and inserted breathing tubes, allowing air to pass directly to the lungs. Doctors avoided using anesthetics and sedatives with polios because of an already-damaged nervous system. Blood spurted and polios, no long able to breathe through their noses or mouths, because of the tube, experienced the reflexive terror of suffocation. The tracheotomies usually worked but the memories of suddenly witnessing one's throat being cut endured. During this initial stage, they experienced searing and unrelenting pain in every part of their bodies. Polios became delirious from the endless discomfort and high fever. Their muscles shrank and stiffened. Their limbs became contorted.⁵

Extreme cases of infantile paralysis created two distinct scenarios. In most of these situations, children experienced partial recovery of muscle use and strength, regaining some of their physical mobility. In the remainder of cases, severe nerve damage or destruction resulted leaving the child permanently paralyzed. Whatever the outcome, misery became a permanent companion: the anxiety created by the onrush of early symptoms, a diagnosis process that usually involved an agonizing spinal tap as well as muscle tests, and a relentless and taxing treatment regimen. In addition to excruciating physical pain and frustrating impairments, these children suffered social rejection from peers in particular and society in general.

A historiographical lacuna exists for the polio experience. The medical role and place of the American public schools has been, at worst, ignored or, at best, relegated to the somewhat obscure field of history of health education or a useful but narrow analysis of the mental hygiene movement.⁷

The history of special education too overlooks the specific impact of this disease on school policy and practice. First, this sub-field generally categorizes physical, emotional, and intellectual needs as organic and, thereby, rarely accounts for a child moving from a non-disabled existence to a disabled one. Second, the history of special education tends to ghettoize the disabled, isolating their experiences from the broader social context.⁸

At the same time, and with few exceptions, the historical literature on poliomyelitis has carefully constructed a pantheon of medical heroes. Its celebratory tone focuses on the medical scientists, like Jonas Salk; institutions, such as the National Foundation for Infantile Paralysis (NFIP); as well as renowned individuals, like Franklin Delano Roosevelt; omitting the 'public' in general and school children in particular. Children — often the actual objects of research — have been overshadowed by the talents of famous scientists and the advances of their medical laboratories, ultimately disappearing from the historical record altogether. The history of education and the history of medicine have, therefore, been treated as discrete entities, or realities. Traditional treatments have maintained a narrow and fixed notion of the physical norm, creating a series of dualities: attractive and repulsive; beauty and ugliness; independence and dependence. Within this framework, physical disability remains a social stigma; more importantly, it 'denies' human agency. 10

Standard views of disability have oversimplified this experience, relegating it to an illness, social deviance, and as a personal problem. If a disability occurred due to medical reasons, the impaired person became dependent on health and rehabilitative professionals and institutions as well as family members. They thus became less than human, losing their dignity. Impairment growing from perceived abnormal and antisocial behaviors led to a 'stigma'. This, in turn, denied the disabled equal rights. Finally, in either case, disability has often been seen as a purely individual quandary requiring individual solutions through physical and mental rehabilitation and acceptance of a new life, adaptation. Therefore, fundamental questions remain. How can we reconstruct the history of education while overlooking the impact of the medical world? How can we illustrate developments in special education while ignoring the disabling effect of certain diseases on children? How can the history of medicine marginalize children, often the subjects of treatment?

This study offers an alternative interpretation.¹² It taps disability history, an emerging field of study. According to historian Catherine J. Kudlick, the disability experience has not operated as an 'isolated, individual medical pathology but instead ... [as a] social category on a par with race, class, and gender'. '[I]mpairment' has represented a subjective

label, historically a moral, social, and/or political categorization of human beings. The medicalization of western society during the late nineteenth and early twentieth centuries, 'created a special role both for the disabled person in society, and for disability as a social variable'. Disability history turns mainstream analysis on its head by viewing humankind as temporarily non-disabled. The majority, if one wants to use that term, maintains a fragile existence. An accident, the physical and mental toll of ageing, and the aftermath of diseases, ensure that anyone will eventually experience a disability. Disability therefore represents as a universal human experience. The notion of disability has been socially constructed not biologically determined. Disability history transcends medical labels because it does not see physical diversity as a pathology. As a result, it challenges the concept of the norm, whatever that may be. 13 And polios have historically fit the definition of disabled: 'first, it is a system for interpreting bodily variations; second, it is a relationship between bodies and their environments; third, it is a set of practices that produce both the ablebodied and the disabled; fourth, it is a way of describing the inherent instability of the embodied self'. 14

By focusing on polios' struggles between 1916 and 1956, we can analyze the litany of public responses as well as how children adapted to their new and painful lives. This study reconstructs polios' experiences through autobiographies, oral histories, and visual sources. Historians have virtually ignored 'illness narratives', or 'pathographies', creating a one-dimensional picture of diseases: a clinically, or institutionally, detached perspective rather than a human experience, with its physical pain and emotional distress. However, '[l]ike women, like people of color, people with disabilities have complex and often hidden histories; these need to be found and explained. Like gender, like race, disability must become a standard analytical tool in the historian's tool chest'. This analysis maintains a two-part agenda: one pieces together society's perception of polios—the public world; another recreates the daily lives of the afflicted—the personal reality. I argue that a sharp dichotomy existed between these two universes.

Paternalism

Society's frantic response to poliomyelitis seemed irrational at first. Infantile paralysis in some ways paled when compared with other contemporary epidemics. Earlier cholera and yellow fever outbreaks produced higher morbidity and mortality rates while the death toll from the 1918 influenza pandemic easily outstripped poliomyelitis, with estimates of over 21 million deaths reported worldwide. Nevertheless, what it lacked in its quantitative impact, compared to other diseases and

epidemics, infantile paralysis compensated in a qualitative sense by permanently changing the lives of millions of people. It evoked deep emotions and constructed an enduring reality. Polio's effects proved to be far less ephemeral than other diseases: it usually attacked children, intensifying sympathy toward these helpless and innocent *victims*; they often remained paralyzed, requiring constant, long-term care and treatment, as well as demanding and expensive assistance from their caregivers; they could at best expect to be *bandicapped* for the rest of their lives. In short, they had experienced the sudden transformation from non-disabled to disabled. And all aspects of their lives changed.

The public typically perceived the polio through a paternalistic lens. For many, the polio and 'Tiny Tim', Dickens's young and vulnerable character, became one and the same. ¹⁹ For others, the presence of the polio produced a sense of revulsion.

Pity

The public's attitude towards those afflicted focused on sympathy, which many polios found to be 'vicarious'. 20 Nothing symbolized this more than the March of Dimes poster child introduced in 1940 (Figure 1). To tap into popular sentiment, the NFIP introduced the March of Dimes. This allowed ordinary individuals to deposit their pocket change in March of Dimes cans at movie theaters and retail stores, or make donations during nation-wide, door-to-door campaigns. Well intended, the poster child became an icon, 'a vibrant model of the ideal polio survivor: well-dressed, well-groomed, full of vitality ...'. Every community hosted 'beauty contests' to select the national poster child. Carol Boyer, who served as the Washington, D.C., winner, found herself displayed for public, fund-raising events and used for a photo opportunity with Vice President Richard M. Nixon in 1953. 21

In retrospect, historian Rosemarie Garland Thomson maintains that the 'poster child is the quintessential sentimental figure of twentieth-century charity campaigns'. The 'viewer', usually an adult, can perform an act of 'heroism' by donating a mere dime (Figure 2).



Figure 1
'Please Join the March of Dimes' Terry Tullos, 1948 poster child (NFIP-771)

... the poster child of the 1940s and 1950s introduced two new elements into the rhetoric of sentiment that disability photography inherited from the nineteenth century. The first is that cure replaces suffering as the motivation for action in the viewer. Whereas the earlier sentimental literature accentuated suffering to mobilize readers for humanitarian, reform, or religious ends, the poster boy's suffering is only the background to his restoration to normalcy that results from 'your dimes'. Sentiment here, then, replaces the intensity of sympathy with the optimism of cure [Figure 3], testifying to a growing faith in medical treatment and scientific progress that developed as modernity increasingly medicalized and rationalized the body in the nineteenth and twentieth centuries. The second new element is ... the self-serving opportunity that charity provides the giver for 'conspicuous contribution.' What is clearest is that this rhetoric of sentiment diminishes the disabled figure in the interest of empowering, enhancing, and enlarging the viewers' senses of themselves.

The poster child campaign operated as an emotional appeal, a clarion call to action. 'Rhetoric is the art of persuasion. By formulating popular

photographic images of disability as visual rhetorics, we cannot only 'read' the content, conventions, and contexts of the photographs but also probe the relationship the pictures seek to establish with the viewer. A rhetorical analysis such as this seeks to illuminate how and what the photographs intended to persuade their audiences to believe or do'. The March of Dimes sought to cultivate public sympathy for the young victims of infantile paralysis, generate donations, supply care and equipment in the short run, and develop a cure in the long run. At the same time, according to Thomson, photographs increase the distance between the viewer and the viewed: 'This inherent distancing within the photographic relationship replicates the social untouchability of disabled people, one of the most oppressive attitudes directed at them. The disabled figure in western culture is to-be-looked-at rather than the to-be-embraced'. Thomson 'proposes a taxonomy of four primary visual rhetorics of disability: the wondrous, the sentimental, the exotic, and the realistic'. Polio



Figure 2
'Fighting in the Dark' — poster by McClelland Barclay, c.1941
(not numbered)

photographs clearly fit into the sentimental category. As Thomson further asserts, '... the sentimental places the disabled figure below the viewer, in the posture of the sympathetic victim or helpless sufferer needing protection or succor'. The March of Dimes poster children therefore portrayed a 'diminished' image 'to evoke pity, inspiration, and frequent contributions'. This produced '... a spectacle of suffering rather than the reality of the suffering ...'. The viewer became the 'benevolent rescuer and the disabled figure as grateful recipient'. In a more fundamental sense, the 'spectator' became the historical agent while the disabled person assumed a passive, if not feeble, role.²²

Rejection

Social ostracism sometimes began with medical professionals. Ambulance drivers and attendants covered potential polios with rubber sheets to contain any suspected contagion. Even some otherwise well-meaning hospital personnel reflexively avoided newly admitted children who had been diagnosed with poliomyelitis. Nurses rarely lingered in the polio isolation ward. Many nurses, in fact, refused polio-patient duty. As a polio left the isolation ward, the hospital staff, fearful of further contagion, burned all of the patient's clothes, flowers, get-well cards, and souvenirs. 23

Another less obvious perspective characterized the public's attitude toward polios. Their actual, physical presence proved to be embarrassing or created discomfort. In the public realm of disability, the seer and the seen exist. 'The dominant mode of looking at disability in this culture is staring.' 'Staring', Thomson contends, 'is the social relationship that constitutes disability identity and gives meaning to impairment by marking it as aberrant'. The starer is 'normal'; the disabled person is not. Starring represents an act of 'exclusion from an imagined community of the fully human'.24 Nine-year-old Marilyn Rogers's first venture into public, after surviving the initial polio infection, both repelled and angered her. She had not been prepared for how people visibly reacted to her as a nurse pushed her down the street in a wheel chair. Hugh Gallagher recalls how people blessed themselves with the sign of the cross as polios wheeled by on sidewalks. Robert Gurney contracted polio in small town Minnesota at age seventeen. As he recalled: 'Outside of school ... sometimes people would look at me like I had some contagious disease'.25 The disabled therefore became 'socially erased'.26 This evokes Ralph Ellison's eloquent portrayal of the African-American experience in the Invisible Man. Charles L. Mee, who contracted polio at age fourteen in Barrington, Illinois, describes how people frequently talked about polios in their presence, referring to them in the third person: 'Well, he's one of the lucky ones -

at least he can get around in a wheelchair, you know; he's not in an iron lung'.27

This social attitude applied to all aspects of life, including sexuality. After a great deal of painful physical therapy, Jean Johnson learned to walk again. However, she quickly discovered that she no longer appeared feminine to men. Polio had stamped her as an untouchable. As she recalls: 'In this kind of culture ... men like perfect women; they like their arms and legs to match. And that was quite a shock to me Right away, you knew where you stood with men and it was just devastating'. Dates and school dances proved to be emotionally traumatic for Josephine Walker; she discovered she too was imperfect in the eyes of her male peers. The general public generally perceived polios as sexually 'neutered', which of course was not true.²⁸



Figure 3 'Look! I Can Walk Again' – Linda Brown, poster child (NFIP-774)

Physical separation represented another manifestation of social rejection. The hospital staff and doctors usually advised that the parents of polios enroll their children in a handicapped school. Some public schools refused to readmit polios, assigning them to a 'special school for handicapped children'. Barb Johnson's kindergarten instructor attempted to remove her from the other students: '... they wanted to put me in special education, and it wasn't special education for kids with physical handicaps. I would have been segregated off into a classroom with mentally handicapped children. I guess they thought that since I was physically handicapped, I must be mentally handicapped as well. Fortunately, my parents wouldn't allow it ...'. Furthermore, school administrators generally relegated polios to classes on the ground floor of the building. Polios often needed assistance to use the toilet at their schools, since none had been adapted. This proved to be demeaning. Finally, at least one school superintendent refused to readmit a polio to school.²⁹

If the sight of polios proved to be discomforting, removing them from the general population solved the problem. Wheelchair-bound polio patients experienced considerable discrimination. Highly visible, they suffered either from public displays of pity or social rejection, leading contradictory lives. In the former case, well-intentioned individuals showered them with sympathy, publicly humiliating them. In the latter case, the presence of wheelchair patients offended many people. As Marilynne Rogers recalls, 'I was asked to leave a restaurant, because it bothered the other customers ...'. On another occasion, deemed a hazard by blocking the audience's access to exits in case of a emergency, ushers ordered Rogers to leave a concert. Rogers saw it differently: 'It seemed to me that in case of a fire I'd be the one to get trampled. I was the one taking a chance. I left highly insulted'. Rogers, like other polios, discovered her lack of rights and her existence proved to be subordinate one. As a result, she led a highly restricted social and cultural life.

Victims?

Almost overnight, polios and their families faced a disabled reality. Disability has been traditionally viewed as 'pathology'. Medical professionals as well as the general public saw people with disabilities only as 'patients', solely the subjects of 'treatment', or victims 'afflicted with disease'. They therefore appeared one-dimensional with no personal or work lives. Historians, moreover, have too often dehumanized them. But this seems to be changing. 'In recent years, medical historians have increasingly addressed the sociocultural experience of illness and public discourse about disease, health, and health care'. Disabled persons functioned as 'historical actors'.³¹

The polio who, prior to infection, may have viewed the disabled as deficient and less human now had to grapple with this profound identity transformation. The normal had become abnormal; the strong had grown weak; the independent had turned seemingly dependent. Fred Davis, based on his 1954-55 sociological research, writes that the polio's

attempts, if any, to be accepted by 'normals' are doomed to failure and frustration: not only do most 'normals' find it difficult to include the handicapped person fully in their own category of beauty, but [the polio] shares the 'normal' standards of personal evolution, will in a sense support their rejection of him. For the fact remains that, try as he [sic] may to hide or overlook it, he is at a distinct disadvantage with respect to several important values emphasized in our society: e.g., physical attractiveness; wholeness and symmetry of body parts; athletic prowess; and various physiognomic attributes felt to be requisite for a pleased and engaging personality. ³²

Nevertheless, a sense of 'polio pride', seen as a part of 'disability pride', existed. As Charles Mee asserts: 'We felt like survivors, even heroes'. 33 And polios responded in a variety of ways, usually based on age.

Polios' experiences diverged between elementary and high school. Generally speaking, polios found a modicum of acceptance and comfort at the elementary level. The school's social world shaped the self-identity of younger polios who, in the beginning, appeared to be quite oblivious to their disability. 34 First, in formal social situations, their physical appearance, from the subtle but odd shape of orthopedic shoes to the more pronounced metallic clink of leg braces, signaled that they were different. Joan Headley, who contracted polio at an extremely young age in a small town in Indiana, represents a case in point, moving from a state of unawareness, or even innocence, to stark realization. In elementary school, she remained totally oblivious to her limp, a polio legacy. She even stood in line to receive the polio vaccine at her school. She describes her epiphany: 'The little boy standing next to me said, "Why are you taking this?" I looked at him and thought, "Why shouldn't I?" Then all of a sudden it occurred to me: all this fuss was for something I had had - and it didn't even hit me'. 35 Second, their inability to 'participate' in baseball, dancing, roller skating, and swimming limited their informal social-interaction opportunities; play eventually became isolated, a lonely, individual act. Third, peer 'associations' shifted. Pre-polio friendships rarely, if ever, endured. This transformation proved to be gradual but nonetheless emotionally unpleasant. Classmates at the handicapped schools often became substitutes. Still the regular and frequent rhythm of prepubescent as well as adolescent social interactions deteriorated to random and scheduled weekend visits with other polios who did not necessarily reside in the same neighborhood.

Older polios responded in any one of three ways, none of which appeared to be mutually exclusive. First, some tried to act normal, refusing to wear their braces or attempting to ride the school bus. Charles Mee plunged into normal life and its routines, including home: 'There was no special equipment for getting in and out of the bath, nothing special to hold on to except the ordinary banister for going up and down stairs. nothing altered in my bedroom. I learned to accept the world as it was and to adjust to it ...'. Determined to recapture his previous life, he hid his crutches from view when someone photographed him. Others tried to make their new reality normal. After being hospitalized, David Kangas had to complete his last two years of high school. In an era that lacked mandated adaptations, he faced many obstacles. Permanently confined to a wheelchair, Kangas required a great deal of assistance from classmates to attend classes because '[t]here were no elevators, so in order to get to the upper floors, a crew of several students would have to grab my chair and lift me up the steps'. Kangas, a former high school athlete, did not like this feeling of physical helplessness: 'However, I just had to face up to the fact that it was the only way I was going to get up to those other classes and continue with my schooling. For the most part, the guys who helped me were quite willing to do it, but I sure didn't like it'. School administrators also re-scheduled some classes for him on the first floor and assigned a student to monitor him. Nevertheless, he still found it awkward to attend informal school functions.36

Acutely aware that they were now different, they participated in activities as though nothing had happened whatsoever. While physically disabled they were intellectually normal. Purposeful compensation took place, shifting from physically demanding activities, like athletics, to more cerebral outlets, like debating. A social outcast in high school, Mary Ann Hoffman experienced this shift: 'I remember going to the freshman dance. I was all excited about it, but no one asked me to dance all night! I was just crushed ...'. She transferred to another high school in tenth grade and, proving to be resilient, attempted to control her social world by participating on the student council, editing the yearbook, selling tickets at sports events, going on dates, attending dances, and eventually becoming class valedictorian.³⁷

School dances further separated polios by gender. Girls felt incredibly self-conscious and more often experienced rejection. Disability made a woman's body 'asexual and unfeminine'. Boys, however, found it easier, more socially acceptable, to attend school socials, like the homecoming celebration or the prom. Charles Mee, a former high school football player, donned his white tuxedo and took Suzy, a cheerleader, to the junior prom: 'We danced. That is, she moved with me. I had figured out how, with one

hand on her waist and my other hand steadying myself by holding my own hip, I could stand and move a few steps without my crutches. She let one arm rest lightly on my shoulder, one hand took me lightly but supportively at the waist, and we moved to the music.' Many polios confronted the 'cultural stereotype'. Lorenzo Wilson Milam and a female polio actively engaged in kissing, petting, and other sexual activities.³⁸

Second, others retreated from 'normals'. 39 Anger and resentment, even shame, shaped the outlooks of many polios. Their emotional trauma matched the physical catastrophe. And their world became one of them versus us. As polio Leonard Kriegel expressed it: '... the dirty little secret of anyone who's lived with polio - or any severe disability - on intimate terms is that after a while you come to feel a certain contempt for people who haven't'. 40 Some, like Kriegel, internalized this bitterness while others struck back. Joan Headley, while undergoing physical therapy at the D. T. Watson Home for Crippled Children, near Pittsburgh, and other polios retaliated against cruel nurses and hospital staff members by creating more work, all of it maintaining an innocuous appearance but surreptitious nevertheless: 'We'd go in and leave the showers on and put the plugs in the tubs. We'd spill our food on our beds and then say, "Oh, it was a mistake", you know ...'. Furthermore, such social polarization required polios to collectively plot and execute their revenge in unique and clever ways: 'When we pulled one of these capers, you'd get somebody with hands to help somebody that could use their feet. I mean, we had to take a combination of bodies to be able to pull these things off, so that you knew people by what they could help you with, or what they were able to do, not by what they couldn't do. Which, of course, is essentially opposite to the view of the outside world'.41

Polios therefore saw the world divided into two distinct cultures: the polios and the non-polios. Richard Owen, stricken with polio at age twelve in 1940, found himself the 'only disabled person in a student body of about 3,000'. He wore a leg brace. His social life, because of numerous school absences and impaired mobility, proved to be limited. According to Owen, 'I had ... become a slow-moving person, and that was something that was really difficult for me, particularly in high school. I ended up walking alone much of the time'. 42

As we have seen, polios appeared to encounter few academic problems but did perceive social barriers, whether inflicted or self-imposed. Gail Bias recalled her transitions: At first, 'the kids in school used to laugh at me ...'. After a while, however, her classmates accepted her and invited her to play at recess. By the time she reached high school, and even though she regained some mobility, she avoided social events, like dances, and extracurricular activities, such as cheerleading; she simply felt too

self-conscious. 43 Gail Bias moved from reluctant acceptance to total avoidance.

A few experienced a complete emotional collapse. Feeling self-pity and discouraged, as well as generally depressed, they disassociated themselves from the normal world, severing all organizational ties, such as the Boy and Girl Scouts. Classmates taunted polios, calling them 'cripples' or 'sissies'. Overwhelmed with 'self-conscientiousness', some chose self-exile; they avoided educational opportunities, employment, and became 'prisoners in their own homes'. 44 Unable to cope with her disability, Marilyn Rogers attempted to starve herself to death until a doctor intervened. In the most extreme case, two teenage boys who had been high school football stars became emotionally distraught over the loss of their athletic skills: they would no longer play a sport they loved and jubilantly celebrate their team victories. The symbol of their masculinity had suddenly disappeared. They faced a new reality dominated by the frustration of physical immobility and the trauma of becoming social outcasts. They committed suicide while undergoing physical therapy at the D. T. Watson Home for Crippled Children in the late 1940s. 45

Third, still others acted in a positive manner and insulated themselves from pitiful stares and condescending attitudes by creating an accepting and tolerant social environment of friends and acquaintances. Jack Dominik, who contracted polio in 1925 at three years of age, avoided school recess because he could not participate in many physical games. His classmates, rather than tease him, actually helped: 'One boy used to walk home with me every day and make sure I got safely across a busy street'. ⁴⁶

Generally speaking, polios detested pity because it connoted inferiority; instead they tended to view themselves as survivors not victims.⁴⁷

Conclusions

The polio experience is compelling from a number of standpoints. The virus did less to create disability than the fact that polios deviated from the norm. They too often became social outcasts, either through compulsion or by choice. They saw their functionality reduced by the lack of accommodations in public places, including schools. Disability, in short, is socially constructed.⁴⁸

When we speak of the physically disabled, we too often link this to a condition that began at birth. This was simply not the case with polios. They had led non-disabled lives and suddenly had to cope with disabled ones. A disease not only contributed to their new self-identities but their social environments changed it as well. Their families and peers, who had first loved and befriended a non-disabled person, often altered their

perceptions. They too saw someone different, and in extreme cases less human. The polios' physical appearance transformed both their public and personal realities. And as historical actors they responded in many different ways. Polios through their medical, physical, and social experiences created 'a new model for disability'.⁴⁹

Educational history marginalizes the disabled and special education ghettoizes it. The polio experience represents an integral part of the history of schooling, yet it remains outside of the mainstream. Medical history stresses the clinical and hagiography, largely ignoring the polio patient. All of these genres of history tend to overlook the lives of schoolaged children, lives permanently changed by disease. The non-disabled became disabled. A beautiful child, because of social and cultural norms, became the focus of pity or rejection. As they analyze the impact of race, social class, and gender, historians must incorporate the disabled into their narratives. The story of these invisible children needs to be told, pondered, and debated.

Notes

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- 1. Charles Dickens, A Christmas Carol (New York: Penguin Books, 1984), 88.
- 2. Haven Emerson, The Epidemic of Poliomyelitis in New York City in 1916 (1917; reprint, New York: Arno, 1977),11; Kenneth F. Kiple, ed., The Cambridge World History of Human Disease (Cambridge: University of Cambridge Press, 1999), 942; Nina Gilden Seavey, Jane S. Smith, and Paul Wagner, A Paralyzing Fear: The Triumph Over Polio in America (New York: TV Books, 1998), 23; Charles L. Mee, A Nearly Normal Life (Boston: Little, Brown & Co., 1999), 5, 51-52.
- 3. Mee, A Nearly Normal Life, 5; Seavey, Smith, and Wagner, A Paralyzing Fear, 170. Annual statistics proved to be notoriously unreliable because mis-diagnoses may have indicated polio when it did not exist, or overlooked it because of flulike symptoms. Sharon Barnartt and Richard Scotch, Disability Protests: Contentious Politics, 1970-1999 (Washington, D.C.: Gallaudet University Press, 2001), 14.
- 4. Fred Davis, Passage through Crisis: Polio Victims and their Families (Indianapolis, IN: Bobbs-Merrill, 1963), 4-5. Davis provides a solid analysis of 14 polio families, largely working class, based on occupation and years of schooling, and white, who resided in the Baltimore metropolitan area. His sample included 8 boys and 6 girls, ages four through twelve. Davis's longitudinal, pre-Salk (1954-55) vaccine study relied on in-depth, 'open-ended' interviews of family members, including the polios themselves. Also, as Davis, a sociologist points out, 'in an 'average' pre-1955 year, the incidence rate among

children in this age group living in metropolitan areas of the United States was approximately 50 [per 100,000].' The polio infection rate during the 'notorious' 1931 New York and 1947 Berlin outbreaks jumped to 226 and 360 per 100,000, respectively. For additional methodological information, see 3, 182, 183, 188-90. See as well Kiple, ed., Cambridge World History of Human Disease, 944-45.

- 5. Lorenzo Wilson Milam, *The Cripple Liberation Front Marching Band Blues* (San Diego, CA: Mho & Mho Works, 1987), chapters 1 & 2. For a description of the tracheotomy procedure, see 5-6.
- 6: Tony Gould, A Summer Plague: Polio and its Survivors (New Haven: Yale University Press, 1995), uses the term 'polios,' i.e., persons with polio, 43. Also refer to Mee, A Nearly Normal Life, 17, 18, 28; Kiple, ed., Cambridge World History of Human Disease, 942.
- A paucity of literature exists in the history of health education. Standard works, such as Richard K. Means, A History of Health Education in the United States (Philadelphia: Lea & Febiger, 1962), tend to maintain a traditional narrative approach. Meanwhile, disease has played a secondary role in textbooks used in teacher-preparation courses. Charles C. Wilson, ed., Health Education: A Guide for Teachers and a Text for Teacher Education (Washington, D. C.: National Education Association, 1948), published several years before the discovery of the Salk vaccine, made suggestions (see pp. 217, 219) about using polio as a topic based on the season of the year or the delay of the school year because of 'an epidemic of poliomyelitis.' In the immediate post-Salk era, teacherpreparation textbooks, like Delbert Oberteuffer, School Health Education: A Textbook for Teachers, Nurses, and Other Professional Personnel (New York: Harper & Row Publishers, 1960), in chapter 14, acknowledge the disabling impact of diseases. Nevertheless, they portray the 'handicapped' as students who 'seriously deviate from the normal' (p. 399) and simply lump them together, in a monolithic manner, with students who have sight and vision disabilities. I want to thank a kind colleague, Michael Cleary, Slippery Rock University, for sharing those early health education sources with me.

Sol Cohen's classic work on the existing medicalization model in the history of education focuses on the mental hygiene movement, encapsulated in Challenging Orthodoxies: Toward a New Cultural History of Education (New York: Peter Lang, 1999). See chapters 7, 8, 9, 10, 11, in particular. Recent challenges or elaborations of this important historiographical development have recently emerged. Stephen T. Woolworth, 'Conflict, Collaboration, and Concession: A Study of the Rise and Fall of Medical Authority in the Seattle Public Schools, 1892–1922' (Ph.D. diss., University of Washington, 2002), offers another analytical model.

8. For the standard and most comprehensive history of special education in the United States, see Margaret A. Winzer, The History of Special Education: From Isolation to Integration (Washington, D. C.: Gallaudet University Press, 1993). Winzer's index makes no reference to disease-induced disabilities in general and poliomyelitis in particular. Rosemarie Garland Thomson, Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature (New York: Columbia University Press, 1997), 15, is especially helpful in analyzing special education and disability theory.

- 9. Well-known examples include John R. Paul, A History of Poliomyelitis (New Haven: Yale University Press, 1971), and Jane S. Smith, Patenting the Sun: Polio and the Salk Vaccine, The Dramatic Story Behind One of the Greatest Achievements of Modern Science (New York: William Morrow and Co., 1990). Aaron E. Klein, Trial by Fury: The Polio Vaccine Controversy (New York: Charles Scribner's Sons, 1972), and Naomi Rogers, Dirt and Disease: Polio Before FDR (New Brunswick, NJ: Rutgers University Press, 1996), provide the few critical treatments. Klein still dwells on the researchers and organizations while Rogers somewhat deviates by focusing on the impact on poor and immigrant families. They, therefore, largely relegate the public schools to minor roles at best and totally ignore polios at worst.
- 10. Thomson, Extraordinary Bodies, 9-10, 11.
- 11. Barnartt and Scotch, Disability Protests, 34-35.
- 12. I first experimented with this framework in a paper, 'Life with Polio,' presented at the European Conference on Educational Research, Network 17, University of Crete, September 20-25, 2004. I want to thank Ian Grosvenor, University of Birmingham, for his interest and insightful comments.
- 13. Catherine J. Kudlick, 'Disability History: Why We Need Another 'Other,''

 American Historical Review June 2003. See, as well, Thomson, Extraordinary

 Bodies, 6, 13-14. http://www.historycooperative.org/journals/ahr/108.3/kudlick.html (29 Apr. 2004), paragraphs #2, 3, 15, 22. Also refer to Paul K.

 Longmore and David Goldberger, 'The League of the Physically Handicapped and the Great Depression: A Case Study in the New Disability History,' Journal of American History 87 (December 2000), 888-922; Paul K. Longmore and Lauri Umansky. 'Disability History: From the Margins to the Mainstream,' in The New Disability History: American Perspectives, eds. Paul K. Longmore and Lauri Umansky (New York: New York University Press, 2001), 3, 15; Thomson, Extraordinary Bodies, 22-23.
- 14. Rosemarie Garland Thomson, 'Seeing the Disabled: Visual Rhetorics of Disability in Popular Photography,' in *The New Disability History*, 348.
- 15. Oral histories and interviews of polios prove to be invaluable, authentic evidence. However, my research reveals that polios' autobiographies or memoirs express deeper emotions, expose inner struggles. Why? Could it be that the interviewer, either through the editing process, or by eliciting particular responses from the narrators, or by the mere fact of being present, unwittingly acts as a filter? Philip Gardner and Peter Cunningham, 'Oral History and Teachers' Professional Practice: A Wartime Turning Point,' Cambridge Journal of Education 27 (November 1997), 337-40, begin to address this matter in a more theoretical manner.
 - This particular study attempts to synthesize these individual autobiographies, interviews, memoirs, and oral histories into a collective experience.
- 16. Daniel J. Wilson, 'A Crippling Fear: Experiencing Polio in the Era of FDR,' Bulletin of the History of Medicine, 72 (1998), 467.
- 17. Paul K. Longmore and Lauri Umansky, 'Disability History: From the Margins to the Mainstream,' in *The New Disability History*, 15. Wilson, 'A Crippling Fear', 494, keenly recognizes this historiographical lacuna, albeit much larger than even he realizes: 'In focusing on the larger developments in the history of poliomyelitis, historians have largely overlooked the daily struggles of those

struck down by the virus.' See, as well, Barnartt and Scotch, Disability Protests, xviii-xix.

A few studies, like Edmund J. Sass, with George Gottfried and Anthony Sorem, Polio's Legacy: An Oral History (Lanham, MD: University Press of America, 1996), focus more on the everyday lives of polios. In a similar vein, Tony Gould's, A Summer Plague: Polio and its Survivors (New Haven: Yale University Press, 1995), maintains a two-part study with the first synthesizing secondary sources to produce a comprehensive, but general, context and the second using oral histories from England and America.

Also, see James B. Gardner and George Rollie Adams, eds., Ordinary People and Everyday Life: Perspectives on the New Social History (Nashville, TN: American Association for State and Local History, 1983), for a now, classic overview of the social history framework, as well as David Montgomery, 'History as Human Agency,' Monthly Review 33 (Oct. 1981), 42-48

- Alfred W. Crosby, 'Influenza,' in The Cambridge World History of Human Disease, ed. Kenneth F. Kiple (Cambridge: University of Cambridge Press, 1999), 810
- 19. Leonard Kriegel, 'Uncle Tom and Tiny Tim: Some Reflections on the Cripple as Negro.' American Scholar (Summer 1969), 417.
- 20. Mee, A Nearly Normal Life, 39.
- 21. Seavey, Smith, and Wagner, A Paralyzing Fear, 77-78. The quotes are from pp. 74 and 92, respectively. Milam, The Cripple, 54-55, castigates the sanitized image portrayed by the polio posters:

Those adorable little girls, in their pinafores, with the clear little blue eyes, and their sweet rosebud mouths. And their little crutches, and their tiny exquisite little braces on their little limbs.

What a pretty disease! No drooling or twitching here! No shitting down the leg, convulsions or other indecent exposures.

- 22. Thomson, 'Seeing the Disabled,' 339-40, 341, 342, 355; the indented quote is on p. 356. Davis, Passage through Crisis, 6, reinforces Thomson's point: Polio, unlike any other disease, evoked a strong, emotional public response. It came 'to occupy a pre-eminent according to some, an exaggerated place in the awareness, sympathy, and philanthropy of the American people. By the time of the development of the Salk vaccine it had emerged in popular thought as more than a sometimes crippling disease of children; it was regarded as a powerful symbol of blind, devastating, and uncontrollable misfortune whose victims were specially entitled to the support of good will of the community.'
- 23. Mee, A Nearly Normal Life, 14, 15-16, 24, 28, 29.
- 24. Thomson, 'Seeing the Disabled,' 346, 347. Also, refer to Wilson, 'A Crippling Fear,' 487.
- 25. Rogers's and Gallagher's recollections can be found in Seavey, Smith, and Wagner, A Paralyzing Fear, 32 and 55, respectively. Gurney's oral history is quoted in Sass, Gottfried, and Sorem, Polio's Legacy, 28.
- 26. Thomson, 'Seeing the Disabled,' 348.
- Quoted in Mee, A Nearly Normal Life, 76. Mee, p. 131, felt like a 'Negro,' watching a world he could never realize, an outsider looking in. Ralph Ellison, Invisible Man (New York: Vintage Books, 1952). For Kriegel, 'Uncle Tom and Tiny Tim,' 414, 'Uncle Tom and Tiny Tim are brothers under the skin.' The sight of a polio embarrassed people; they simply did not want to see a 'cripple.' The

presence of a polio, he continues on pp. 416-17, made people uncomfortable: 'For the cripple, the black man is a model because he is on intimate terms with terror that does not recognize his existence... . He is in the process of discovering what he is, and he has known for a long time what the society conceives him to be... . What he has been forced to learn is how to live on the outside looking in.'

- 28. Jean Johnson is quoted in Gould, A Summer Plague, 278. The 'neutered' quote can be found on p. 219 while Josephine Walker's recollections are on p. 284.
- 29. Davis, Passage through Crisis, 87, 149; the quote is on p. 93. Johnson is quoted in Sass, Gottfried, and Sorem, Polio's Legacy, 86. Also, see Seavey, Smith, and Wagner, A Paralyzing Fear, 156.
- 30. Marilynne Rogers is quoted in Sass, Gottfried, and Sorem, Polio's Legacy, 59.
- 31. Longmore and Umansky, 'Disability History,' 7-8. Wilson, as previously noted in 'A Crippling Fear,' 467, is more direct.
- 32. Davis, Passage through Crisis, 138. Davis provides a useful analytical framework organized through the experiences of younger and older polios. Refer also to Mee, A Nearly Normal Life, 119-20.
- 33. See Gould, A Summer Plague, 216, for the former quotes. Refer to A Nearly Normal Life, 86, for Mee's commentary.
- 34. See Davis, Passage through Crisis.
- 35. Headley's oral history is quoted in Gould, A Summer Plague, 295.
- 36. Mee, A Nearly Normal Life, 121. Kangas is quoted in Sass, Gottfried, and Sorem, Polio's Legacy, 65.
- 37. Hoffman is quoted in Sass, Gottfried, and Sorem, Polio's Legacy, 140.
- 38. The quotes are from Thomson, Extraordinary Bodies, 25, 27. Mee, A Nearly Normal Life, 168-69, 171; Milam, The Cripple, 77-81.
- 39. Davis, Passage through Crisis, 138, 139, 140, 141, 143, 144, 145, 147, 151, 154. 'Normals' is quoted on p. 140.
- 40. Kriegel is quoted in Gould, A Summer Plague, 282.
- 41. Headley is quoted in Gould, A Summer Plague, 277. Refer, as well, to Mee, A Nearly Normal Life, 34.
- 42. Owen is quoted in Sass, Gottfried, and Sorem, Polio's Legacy, 33.
- 43. Bias is quoted in Sass, Gottfried, and Sorem, Polio's Legacy, 80, 80-81, 82.
- 44. Wilson, 'A Crippling Fear,' 487.
- 45. Seavey, Smith, and Wagner, A Paralyzing Fear, 29; Gould, A Summer Plague, 277. See, as well, Mee, A Nearly Normal Life, 44. Milam, The Cripple, 109, comments that thoughts of suicide proved to be prevalent among polios who sought an escape from anger, helplessness, shame, and pity.
- 46. Dominik is quoted in Sass, Gottfried, and Sorem, Polio's Legacy, 171, 173-74.
- 47. Mee, A Nearly Normal Life, 123.
- 48. Barnartt and Scotch, Disability Protests, xxiii.
- 49. Seavey, Smith, and Wagner, A Paralyzing Fear, 234. Children too became the objects of polio testing, with public school facilities operating as extensions of medical laboratories during the 1950s. This experience, however, does not represent a part of this study's agenda.