

I. Introduction:

In his narrative of a young polio victim, historian and polio survivor Daniel Wilson notes “the sense of fear was omnipresent, from parents, doctor, and the nurses who wheeled you down long corridors, past closed doors to the isolation ward.” America’s polio epidemics traumatized many; children, for example, were subjected to lengthy hospitalizations and forced family separations, situations compounded by silencing, denial, suppressed memories, and exclusion from society. As polio survivors aged, many began to process suppressed memories, resulting in a flood of narratives and testimonies from the 1960s through today.

Reading these accounts reveals how America’s midcentury polio wards reverberated with sound and music. Yet despite extensive scholarship on polio—particularly the race to develop the vaccine—sound’s connection to polio has received little critical attention. Building on musicologist Jenny Johnson’s work on how involuntary memories “emerge primarily through the language of sounds,” and weaving together testimonies of polio survivors, midcentury medical, psychological, and music therapy publications, media coverage and charity campaigns, and theory from trauma scholars such as Van der Kolk and Allan Young, this paper analyzes the echoes of America’s midcentury polio epidemic. Ultimately, I demonstrate how polio’s soundscapes were intimately connected with the body, medicine, illness, and traumatic memory.

First, a few limitations, definitions, and cautions about my presentation today: this is work in progress on a larger project studying intersections of music and sound with polio—from *musicians* whose life stories connect in some way with polio, to *music*’s role in fundraising for a polio vaccine (including FDR’s nationwide birthday balls and the March of Dimes) to *music* somehow connected with polio to mid-century music therapies and polio.¹ Today, however, my focus is exclusively on a *single* piece of this project: memories of mid-century medical

II. Groundwork: caveats & scope, sources, disciplines

soundscapes in American polio wards and rehab institutions. I focus on the United States—primarily accounts of polio epidemics from the 1930s through 1950s—due to the source materials, yet I want to acknowledge the importance and difference of polio epidemics in other places and eras.² In this work I preserve self-referential terms individuals who have contracted polio use to identify themselves, but I also use “polio patient” and “polio survivor.”³

Sources for this work include period medical publications, journalism, and archival material, but mainly I have relied upon hundreds of published polio narratives and polio oral histories from the 1910s through today.⁴ These narratives are crucial in centering *self*-representation, de-emphasizing the “warrior scientist” and race-to-the-vaccine tropes common in polio histories.⁵ The narratives present a compelling set of questions, many with particular import for studying trauma. *Who* made this choice to share their story, and among this who, *whose* voices are overrepresented or marginalized within this corpus of narratives?⁶ There was no universal polio experience, rather vastly different trajectories based on nationality, age, race, class, gender, geography.⁷⁸ Notably, some of these narratives are *not* from polio survivors themselves; rather, they are the printed words of children, siblings, spouses, recalling their connections to their loved ones through the prism of experiencing polio together.⁹ This does not negate their importance—indeed many are poignant memorials, others assistive works for loved ones who through mechanical or other reasons could not write their own stories.¹⁰ *What* is the impetus to not just write these narratives, but to publish them and share them with the public? *When* do these stories emerge? Historian and polio survivor Marc Shell was not unusual in publishing his story in the late 1990s, forty years after his initial illness. These long silences and periods of processing remind us of central questions about trauma, time, and memory, as polio

Aside about the stereotype of the March of Dimes child as the exclusionary “stereotype” of a polio survivor; moreover Rosemarie Garland Thomson notes March of Dimes posters as examples of the “sentimental” in disability representation .

survivor Anne Finger lyrically describes in my quote from her memoir.¹¹ In reading these stories, *what* roles do they play in both expressing personal experience and aligning with collective historical tropes about polio? Historian and polio survivor Daniel Wilson, for example, believes whether “overcoming” narratives are overrepresented in polio writing, whereas Anne Finger has critiqued the “elegiac” narrative trope.¹² Indeed, these narratives raise many questions about how to understand genre and trope in trauma stories.

This work exists at the intersection of disciplines: trauma studies, musicology, sound studies, media studies, psychology. One of the most important is disability studies, which provides crucial ways to understand polio’s social and historical contexts. Disability studies gives us important context on how the mid-century American emphasis on “hard work to ‘overcome’” and “disavowal of emotion or self-pity” fits into period discourse on disability.¹³ Polio survivors often had a fraught relationship with the concept of disability;¹⁴ chronology is important, since many experienced illness before the mainstream disability rights movement in the United States (though some early disability activists in fact *had* impairments from polio). Disability studies also helps us parse complex intersectionalities, as the lives of polio survivors were impacted in important ways by age, class, geography, gender, and race. Historian and polio survivor Daniel Wilson has written about polio’s impact on masculinities, while Naomi Roger’s foundational scholarship analyzes the medical racism of polio epidemics.¹⁵ Finally, an essential way disability studies frames this work is through a powerful critique of medical discourse and our national traumas of institutionalization. Revisiting the sounds and music of medical and institutional experiences through polio survivor narratives, these are frequently *extraordinarily* painful memories in which medicine and institutions are a major source of trauma.¹⁶¹⁷

Turning to a few brief examples of mid-century medical soundscapes in the thousands of polio wards and rehabilitation centers scattered across the country, I'll begin by analyzing the ward sounds, then turning to the musicking within these spaces.

A. Ward Sounds

I begin with the remembered sounds echoing through these institutions. Many polio patients claimed that immobility or the disease itself rendered them specifically attentive and sensitive to sound. While lying immobilized in an El Paso hospital in 1952, Bob Axtell noted that “he developed an acute interest in whatever he could see and hear.”¹⁸ Marc Shell argued that “like most polios, I was very sensitive to noise and needed more quiet than my rambunctious younger brother.”¹⁹ Charles Mee lyrically describes his time in an isolation ward in Elgin, Illinois in 1953, noting not just remembered sounds and repressed memories, but of a beloved sound: straining to hear the sound of his mother’s high-heeled shoes—utterly distinct from those of anyone else’s mother.²⁰ Anne Finger, writing of her surgery in Utica Children’s Hospital, recalled “the clatter of the hard rubber wheels of the wheeled stretcher against the linoleum floor, the echo of that clatter off the walls of the corridor, the squeaking of [the nurse’s] rubber-soled shoes on the floor.. the soft, plaintive groan the elevator gave off as its doors parted to admit us.” Finger muses that while these might be “ordinary” sounds for the nurse, they terrified *her*.²¹ Others recalled squeaking of wheelchairs in rehab centers (or even trying to quiet such squeaks in order to move unobserved by medical personnel).²² Distinct phases of the illness often had their own particular sound markers; Finger writers vividly of her recollections of the hydrotherapy pools at the Utica hospital, recalling the echoing of voices, sloshing sounds, the

clanking of weights—moreover, she felt a “sense of familiarity and shock” when she heard those precise sounds again decades later in a film about wounded Vietnam war veterans.

For some, the most unnerving ward sounds were the respirators and the infamous “iron lung.” The iron lung, often anthropomorphized as a “monstrous animal” in polio accounts, was remembered with powerfully onomatopoeic language.²³ It boomed, it wheezed, it whooshed.²⁴ These sounds permeated the wards; survivor and historian Daniel Wilson notes that “in many hospitals polio patients could hear the rhythmic sound of the bellows moving air in and out of paralyzed lungs elsewhere on the floor.”²⁵ These rhythmic sounds were a source of knowledge: knowledge about your own body, knowledge about your friends nearby, knowledge for friends and family as they visited you. Polio survivor Sid Moody wrote movingly that “part of you is alert to any break in the blanking rhythm which jeopardize the life of someone now your friend.”²⁶ Agnes Axtell used this rhythm to assess her husband Bob’s body, writing that “I soon learned to judge his condition by the rhythm of the lung even before I walked into his room.”²⁷ Martha Mason titled her memoir *A Lifetime in the Rhythm of an Iron Lung*, and the title of my paper today comes from Mark O’Brien’s memoir of living in an iron lung.²⁸

Tracheotomies and paralysis left some individuals in these iron lungs unable to speak; many developed a system of whistles and clicks to alert medical personnel that they needed attention. These were far from the only voices and human sounds in wards and rehab spaces: indeed, many polio survivors wrote of the “constant din” of voices of other polio survivors or medical personnel. Susan Richards Shreve became accustomed to post-surgery screaming from other ward mates at Warm Springs: “we were used to that in one another and could sleep through noises of pain and sadness, or talk through them.”²⁹ Martha Mason felt just the opposite,

recalling of her time in a Morganton, North Carolina polio ward that “the noise of children crying and nurses talking kept me awake.”³⁰

B. Musicking in Wards and Rehab Centers

Turning to musicking in wards and rehab centers, a diverse set of musical and listening practices emerge in polio narratives. These wards were also *communities*, and we certainly see evidence of therapeutic communal music-making and listening.³¹ Singing—informal, improvised, communal—was common. Recalling her time at the Sheltering Arms Hospital in Minneapolis in 1949, Peg Kehret wrote of laying in the dark at night, singing everything from lullabies to rounds to campfire songs and top radio hits, harmonizing with her ward mates Shirley and Alice.³² [we might think of women’s voices & Laura’s keynote]

Musicians—professional, amateur, family friends—regularly visited wards and rehab centers to play or sing for polio patients. Warm Springs in Georgia offered perhaps the most elaborate music making; with square dances, “old-time fiddling” and banjo playing, even “Poliopolitan Opera Company” productions in the 1930s. Intended to assist the communal spirit of Warm Springs, these musics signal a conjunction of medical and musical racism. Not only did Warm Springs have much more elaborate musical options than the Tuskegee Infantile Paralysis Center,³³ archival materials from Warm Springs detail local Black musicians performing for the all-white Warm Springs patients AND Warm Springs administrators giving blackface performances throughout the 1930s and 1940s.³⁴

Probably the most beloved sounds came from radios, a cherished and valuable commodity in polio wards and rehab centers. Many polio narratives recall the day a radio arrived on the ward (or receiving one as a gift from a departing fellow patient).³⁵ Occasional grumbles

about lack of agency emerged—being forced to listen to the programs your ward mate liked!—but mostly these narratives recall the immense pleasure in listening. Preferences varied, from sports to period radio programs. Radios also helped bridge the distance to communities outside the hospital; local DJs dedicated songs to polio patients, and Charles Andrews even recalls writing a song for his son, which played over the air at the local radio station and into the boy’s bedroom at a polio hospital.³⁶

Sometimes these radio sounds served as distinctly therapeutic adjuncts; one polio patient remembered nurses found it easier to administer meals and treatment while he relaxed and listened to the radio. Indeed, listening habits, therapeutic adjuncts, and uplift rhetoric coalesced in these midcentury wards. Amongst other things, polio patients were exhorted to listen to “good music” as they recovered.³⁷ Martha Mason penned one of the longest narratives pairing music and cultural uplift;³⁸ writing of her stay in the Asheville Orthopedic Hospital in 1948 Mason details a kind of quasi-“music appreciation” course from her ward mate Mary Johnston Clark Lee, who tutored her in listening to Beethoven. The two spent most Saturdays glued to the Texaco-Metropolitan opera broadcasts, with Lee teaching Mason the stories of the opera and even “quizzing” her knowledge. [mention music therapy beyond my scope today].³⁹

Reading these narratives, it is abundantly clear how many kinds of traumatic circumstances surrounded polio’s social, medical, and historical construction in mid-century America. Polio traumas are complex; it *is* a collective trauma, specific to a generation, yet also an intensely individual spectrum of experiences. We note the interconnected, socially constructed nature medical trauma in this era and for this disease: the lost memories of the illnesses’ acute phase, the pain of certain procedures, the insistence upon isolation leading to grievous family

IV. Music,
Sound, and
Traumatic
Memory:

ruptures.⁴⁰ We notice the cascading impacts of medical racism, of lack of consent and lack of control, and abuse. We note the spectrum of emotions: patients and families were encouraged to be silent about polio, to deny, to forget; Marc Shell explicitly compares polio writing to Holocaust narratives. For midcentury psychoanalysts and rehabilitation physicians,⁴¹ there was often “a focus on rehabilitating the body and a near complete refusal to discuss the psychological,” an encouragement to forget and move on.”⁴² While this “listing” hardly scratches does justice to the depth of these experiences, it hopefully suggests the manifold ways mid-century polio practices spawned a particular complex of interconnected traumas. Now,

Three Theoretical frameworks:

The first questions the ways in which the interactions of the body and mind might have specific ramifications for some polio survivors. In *The Body Keeps the Score*, Bessel von Kolk talks about how being paralyzed during a traumatic experience is often particularly damaging because of what it does to our fight-or-flight self-preservation instincts. Van der Kolk’s work suggests polio symptoms might intensify traumatic experiences, due to paralytic effects on the body occurring in tandem with other traumatic experiences. Certainly the disease’s unique impacts on the body have an obvious potential for other traumatic effects: in some cases, polio destroys nerve cells in the bulbar region which connects the cerebral cortex to the brain stem. Van der Kolk calls the brain stem the ancient, “reptilian” brain in charge of the basic life-sustaining functions of breathe, sleep, pain, and more.⁴³⁴⁴ Moreover, this damage to the brain directly impacts the vagus nerve—as we’ve discussed multiple times at this conference, Stephen Porges’s pioneering research on Polyvagal theory (1994). As summarized by Van der Kolk, polyvagal theory provides us with “a more sophisticated understanding of the biology of safety and danger,

one based on the subtle interplay of the visceral experiences of our own bodies and the voices and faces of the people around us.”⁴⁵ Both these clauses are key—that polio not only potentially impacted the visceral experience of the body to regulate safety and danger, period treatment protocols of isolating polio patients often intensified damage to social support and reciprocity.⁴⁶ Polio therefore, at least for some, seems particularly likely to cause and intensify trauma through these brain-body-societal connections.

My second theoretical framework asks how and why these sounds might be so memorable and important to polio survivors. Here, I build on Jenny Johnson’s pivotal work, which in a different context, has argued that traumatic childhood memories emerge *through* sound, sounds that trigger memories, sometimes repressed memories. Johnson writes that these “long-buried memories of trauma are somehow more embodied than cognitively remembered, stored more in the blood and tissue of torso or limb or the deep, elderly smell-regions of the cerebellum than in the swifter, more evolved, and efficiently streamlined neural pathways of the context....all these sense memories deeply intertwined with sound to an almost synaesthetic degree....it is like the memories are buried deep inside those muscles, held there in tension....and now released.” Johnson’s work is not only a powerful argument for the connection of sound to traumatic memory, but also an invitation to consider how such sound memories—embedded in the muscles, stored in the ancient regions of the brain—might function for polio survivors in particular.⁴⁷ **Sound as both intensely impermanent but also resistant to forgetting. Not *just* children got polio—adults and teenagers did too— but something particular difficult about the nexus of childhood illness, trauma, memory or lack thereof.**

My final theoretical framework is time. We know that trauma devastates our perceptions of time, and that sound—that allegedly ephemeral yet astonishingly enduring phenomena—is complexly interconnected with both time and trauma.⁴⁸ Polio, as a disease, has unique and manifold connections with time. Some might remember the “polio season” (summer in certain places) or perhaps the “polio era” bounded by epidemics then the vaccine. But perhaps most hauntingly, after decades of time, polio returns to survivors in *new* traumatic ways. Known as Post-polio syndrome or Post-polio sequelae, PPS is a “progressive neurological condition combined with chronic joint deterioration,”⁴⁹ a condition “that affects polio survivors years after recovery from an initial attack of the virus.”⁵⁰ Polio survivor and historian Marc Shell writes that “the new symptoms compel many polios to experience some of the original trauma of the disease...both a haunting past experience and a present reality.” Historian Daniel Wilson traces this impact in Dorothea Nudelman’s book *Healing the Blues*, noting how Dorothea had a “severe delayed grief reaction...buried deep in her psyche. Now, reactivated by new losses from post-polio syndrome, the old grief surfaced and plunged her into depression.”⁵¹ Shell deems it “PPSD,” post-polio traumatic stress disorder. In the US, as we move decade by decade away from the polio epidemics of the 1940s and ‘50s, PPS becomes more visible in the 1980s. Intertwining with emerging frameworks of discussing trauma, by the late 1990s there are about 300 support groups for polio survivors with PPS (it’s hard to know for sure how many polio survivors live in the US, but a number certainly in the many thousands). It is often precisely these retraumatizations or discoveries of traumatic memories that prompted the continuing publication of polio narratives of the 1990s and 2000s.⁵² Storied in the body, in so many senses, the sounds and memories of the “polio era” are still with us.⁵³

¹ 1930s: “Brother Can You Spare a Dime?” repurposed as a fundraising tune for NFIP (Shell, p. 142).

1942: Irving Berlin, “At the President’s Birthday Ball”. Recorded by Glenn Miller Orchestra with vocal refrain by Marion Hutton and the Modernaires, 5 January 1942.

1940s: “You’ll Never Walk Alone” from *Carousel* repurposed as a fundraising tune for polio victims (Shell, p. 141).

Filmed were two excerpts from Balanchine’s 1951 ballet *La Valse* (The Waltz), choreographed to Maurice Ravel’s *Valses, nobles et sentimentales* (1911). The waltz, popular since the eighteenth century, often inspired ballet choreographers to evoke lost eras. The critic Anatole Chujoy described *La Valse* as “neo-romantic, permeated with the spirit of the romantic period of the 30s of the past century.”

But he had choreographed a piece in 1944 for a March of Dimes benefit performance for himself and Le Clercq, then a fifteen-year-old SAB student. In it she played a little girl who was stricken with polio, confined to a wheelchair, miraculously healed, and ultimately able to perform a dance of celebration. Balanchine danced the role of Polio. In an eerie sequence of events, in which life imitated art, Le Clercq was stricken with polio at the age of twenty-seven while NYCB was on tour in, of all places on earth, August Bournonville’s birthplace of Copenhagen, Denmark.

When Le Clercq was 15 and one of the brightest lights at Balanchine’s School of American Ballet, she danced the role of a girl with polio in his “Resurgence,” commissioned for a March of Dimes benefit. Wearing a black cape, Balanchine himself played the Threat of Polio. Many years later, he worried that somehow he had brought on the disease.

² While I’ve read memoirs from other periods, I tend not to cite them extensively in this study. See, for example, Douglas, William O. *Of Men and Mountains*. New York: Harper & Brothers, 1950. He was ill around 1916—therefore fell sick at home. It’s also debatable whether he truly had polio or some other childhood illness.

There were tons of worldwide epidemics in the 20th century: Berlin, Copenhagen, Britain—perhaps the larger study will get to those. I’m focusing on the US for the moment both because there was a large number of epidemics that were particularly severe in the US and because of the particular cultural apparatus around this disease in the US; acknowledging the social/historical model of disease. In addition, the various approaches to medical and institutional care—which is one of my main focuses in this particular paper—differs dramatically from country to country.

³ also called infantile paralysis, poliomyelitis.

⁴ Edmund Sass: an important set of polio oral histories. Daniel Wilson’s book built on many oral histories as well. Wilson bases his book on about 150 narratives. narratives written after 1980s usually involve PPS.

⁵ This warrior scientist terminology comes from Anne Finger. It is in reference to the overreliance on Jonas Salk and Albert Sabin in many histories about polio.

⁶ Daniel Wilson notes that we may have an overrepresentation of people who came to terms with their disabilities when we look at polio narratives. also notes mostly white narratives, mostly middle class, they’re from the people who survived.

⁷ Daniel Wilson in particular discusses this concern of “crippled manhood” and how all of this seemed to be caught up in Cold War fears about masculinity and self-worth and American resilience. Others have discussed the anti-immigrant rhetoric of early 20th century polio epidemics. Also the “Protestant work ethic” of many polio sufferers around mid-century. Several scholars have discussed how polio’s impacts on middle-class American children seemed to subvert the American dream rhetoric.

⁸ This is cited by Laurie Straus in her work on Connie Boswell. In her study of disability portrayed in popular photography, Garland-Thomson proposes a ‘taxonomy of four primary visual rhetorics of disability: the wondrous, the sentimental, the exotic, and the realistic’ (ibid., p. 339): the wondrous mode directs the viewer to look up in awe of difference; the sentimental mode instructs the spectator to look down with benevolence; the exotic mode coaches the observer to look across a wide expanse toward an alien object; and the realistic mode suggests that the onlooker align with the object of scrutiny. (ibid., p. 346)

We can recognise instantly that the first three modes operate across a distance, separating the viewer from the viewed, but the fourth is designed to minimise the gap between them; in other words, wonder, sentiment and exoticism are modes of Garland-Thomson illustrates her four rhetorical modes with images drawn from popular photography: the wondrous mode is found in an image of a person rock-climbing in a wheelchair; the sentimental mode is invoked by a vintage March of Dimes poster which depicts a polio-stricken infant; the exotic mode is exemplified by nineteenth-century ‘freak’ photography, and the realistic mode by an official portrait of a contemporary disabled public servant. Garland-Thomson is careful to point out that the modes rarely occur in isolation; they most frequently are found in combination in a single image, so that a variety of responses may be elicited from the viewer.

Garland-Thomson, R. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York, Columbia University)

2001. ‘Seeing the Disabled: visual rhetorics of disability in popular photography’, in *The New Disability History: American Perspectives*, ed. P.K. Longmore and L. Umansky (New York, New York University), pp. 335–74 : This discourse of middle-class noblesse oblige operates on a model of paternalism, often trafficking in children and alluding to the cute, the plucky, the long-suffering, and the courageous, The poster child (figure 13,2) is the representative figure of sentimental rhetoric. This adorable little boy, for instance, transforms viewers into parentified adults by entreating them to deliver him from his impairment. In disability operates as the manifestation of suffering, a seemingly undeniable sign that makes what is internal and unnarratable into something external and narratable, In this way, the visibly disabled body operates as the spectacle of suffering rather than the reality of suffering, which is less representable.''' In other words, visible disability acts as the stigmata of suffering, Such appeals use the sympathetic helpless child to contain the threat of disempower the viewer to act on his or her behalf.

⁹ Very understudied: Marc Shell is one to do this, but notes polio literature by children is often completely overlooked.

¹⁰ In Charles Andrews’s *No Time for Tears*, for example, this “memoir” is written by his father. Agnes Axtell published an account of her husband’s life.

¹¹ Susan Shreve Richards: When I was eighteen, I wrote a novel, never published, called *Wooden and Wicker*, about a girl with mild paralysis who goes to Warm Springs hoping to be accepted as the cripple she is considered in her ordinary world, only to find she's not crippled enough. The book's title refers to the old-fashioned wheelchairs that were in occasional use at Warm Springs during my time there. When I started to write this book, I went in search of the manuscript, hoping to stir my recollections for the place and the people I knew there. I discovered the book among the files of an old friend, and reading it again after almost forty years, which I did before I began this memoir, I was surprised to see that my present memory of what happened and my youthful invention of events were so different. I initially wanted to write this book to make sense of what had happened in the years I lived at Warm Springs, but it's difficult to connect the strings of truth. ...

A reason, maybe the real reason, I never made an effort to be in touch with these people, who were so central to me for an important period of my growing up, is part of the reason I wanted to write this book in the first place. Not so much to discover anyone I'd lost, but to understand why I had wanted to lose them. *Warm Springs: Traces of a Childhood...*

¹² Finger, "'the heartbreaking kids, frozen for all time on the March of Dimes poster...the elegiac narrative.'" *Elegy for a Disease*.

¹³ Mid-century discourse about "self-pity" / toughening up/encouragement to stifle emotion, also this strange narrative that it was only the gifted or strong who contracted polio/encouragement to retreat into intellect as opposed to physicality.

The mind/body conundrum: compensatory policies: some polios make up (compensate) for physical weakness by turning to intellectual endeavors—as painters, writers, and movie directors. (Shell, p. 218).

—Teenage polios often compensate by developing intellectual rather than physical skills. They take advantage of an enforced "quiet" lifestyle to read. Many first-person polio narrative thus include moments like this. (Shell, p. 222). (And will need to balance with the discussion of the myth of positive compensatory behaviors—Shell mentions some testimonies from people who find polio has certainly had no positive effect on their lives!)

Daniel Wilson: P. 186: Faced with their physical limitations, many young polio survivors focused their attention on their classes and excelled in their schoolwork....polio survivors often compensated for their lack of physical ability by throwing themselves into the many other activities mid-century high schools offered and, especially, by becoming good and even excellent students, substituting mind work for physical work. P. 189: Since jobs requiring substantial physical activity were not an option for many polio survivors, many of them went to college after graduation. Sometimes this was paid for by state departments of vocational rehabilitation (for students who would not have been able to pay otherwise). Even polio survivors dependent on iron lungs insisted on going to college.

Might also remember the seven general themes in Oxford handbook: normalcy, otherness, enfreakment, commotion, self-representation, performance, and the myths of autonomy.

there was also at the time often an attempt to differentiate those with congenital disabilities and those who "became disabled" through polio

¹⁴ Marc Shell: In a recent essay on civil rights, Tom Burke puts forward the thesis that "the politics of civil rights and stability was changed forever by the rise of a new generation of disabled people in the 1960s. Attributes this to polio epidemic of the 1950s and the Vietnam War. Shell doesn't necessarily agree. Does point out that polios identify themselves as handicapped persons more rarely than other apparently disabled persons (Shell, p.199). To put it another way, polios are more likely to struggle with such identification precisely on account of the culture of denial, compensation, and triumph in which they have persevered.

¹⁵ Daniel J. Wilson: *Living with Polio: The Epidemic and its Survivors*. Chicago: University of Chicago Press, 2005.

From Anne Finger's discussion of Wilson: Not surprisingly polio affected males and females differently. Daniel Wilson, who himself had polio, has written of how polio "crippled manhood," forcing boys and men consciously to make or remake their masculine selves. "Weak and effeminate, sissies."...Wilson points out that this "anxiety about sissies was caught up in the post-World War II fears about communism and homosexuality. Americans believed that men needed to be strong, resilient, masculine if the nation was to resist the global spread of communism." ...One boy who had had polio overheard his grandmother telling his father that she had read "most of the polio victims will grow up being homosexual because very few of the opposite sex will want to be seen with a cripple. The polio victim will be forced into a life of solitude or homosexuality." ...Both women and men who had had polio faced overwhelming job discrimination. For men such discrimination not only threatened them financially and in terms of status but attacked their masculine identity. ...

Naomi Rogers, "Race and the Politics of Polio: warm Springs, Tuskegee, and the March of Dimes." *American Journal of the Public Health* 97, no. 5 (May 2007): 748-795.

Naomi Rogers, "Race and Polio:" Tuskegee Institute opened a polio center in 1941, funded by the March of Dimes. The center's founding was the result of a new visibility of Black polio survivors and the growing political embarrassment around the policy of the Georgia Warm Springs polio rehabilitation center which Franklin Roosevelt had founded in the 1920s before he became president and which had maintained a Whites-only policy of admission. Not only the norm of race-segregated health facilities of the era, **but also this repeated argument of the era that blacks were not susceptible to polio [eugenicist view of hardy bodies]**. After a decade of civil rights activism, this notion of polio as a White disease was challenged, and Black health professionals, emboldened by a new integrationist epidemiology, demanded that in polio health care should be provided regardless of race, color, or creed.

* From Naomi Rogers, "Polio and Race:" Warm Springs gradually became a refuge for an elite group of the disabled. Merging medical and social rehabilitation, the center gave polio survivors the opportunity to recover physically and mentally. But from the beginning, this refuge was for White survivors only. Typical of the political calculations by Roosevelt's New Deal administration, which fought the Depression with un-precedented federal funding while accepting racist policies that accommodated the Southern status quo, Roosevelt was careful not to challenge what he saw as Georgia's "local customs" and kept the Warm Springs patients, administrators, and medical staff White. There were maids, waiters, body servants, gardeners, janitors, laundresses, etc that were black (by mid-1930s, 43 of 93 employees at Warm Springs are black).

* Walter White reminded Eleanor Roosevelt that segregation at Warm Springs was the reason the NAACP had refused to sponsor a birthday ball. National Urban League similar. Also noted that about \$100,000 lack dollars go to birthday ball monies.

* Pressures from Civil Rights, Cold War.

* First Black child on March of Dimes poster in 1947.

* Tuskegee reserves a large grant from Basil O'Connor. George Washington Carver and work with peanut oil. Also Black hospitals in Nashville, Durham, and Chicago.

¹⁶ Anne Finger, *Elegy for a Disease* uses this phrase.

¹⁷ Anne Finger writes of this: How deeply rooted is the expectation that disabled people should be alone, separated from others, even if we are no longer segregated in institutions? [Tells story about photograph, disabled boy in india, cropping out the non-disabled body from the photo]....

Those enormous institutions housing disabled people that once dotted the landscape may have been shut down, but much of that habit of segregation still persists—a need to isolate, to contain, to keep the disabled body from contaminating the normal. ... *Elegy for A Disease*.

Finger also compares her experience in hospitals to Gramsci's in prisons.

This has major implications: institutionalization, of course, this massive cultural and collective trauma of American experience, this segregation of disabled bodies from view.

¹⁸ Agnes Axtell, *A Polio Memoir*, Airleaf, 2004.

¹⁹ Shell, *Polio and its Aftermath*, 77.

²⁰ Charles Mee, *A Nearly Normal Life* (New York: Little, Brown, and Company, 1999).

²¹ Anne Finger, *Elegy for a Disease*, pp. 107-108.

²² Susan Richards Shreve, "My wheelchair was standard issue, made of wood with yellowed wicker on the seat and back, and it was squeaky so I pushed it softly by Miss Riley's office...." *Warm Springs: Traces of a Childhood at FDR's Polio Haven* (New York: Houghton Mifflin, 2007).

²³ There are literally dozens of first-hand accounts of iron lung biographies. Shell notes these on p. 126 of his work.

Charles Atkins is the account who referred to the iron lung as a "monstrous animal." Anne Axtell remembered her husband's as "a monstrosity painted train-depot yellow."

²⁴ Axtell, "It boomed and wheezed, and boomed and wheezed." Atkins, "'We heard a monotonous hum of an electric motor and a rhythmic "whoosh" as though some monstrous animal were asleep, breathing." Shreve, "I'd been fascinated by the whoosh whoosh of the machine as the air went in and out."

²⁵ Daniel J. Wilson: *Living with Polio: The Epidemic and its Survivors*. Chicago: University of Chicago Press, 2005.

²⁶ Daniel Wilson explains: Hospital staff generally tried to shield other patients from the deaths of ward mates, but patients quickly learned to read the unmistakable signals. Patients accustomed to the rhythmic sound of the iron lungs in the ward knew instantly when one was silenced. As Sid Moody recalled, "part of you is alert to any break in the blanking rhythm which might jeopardize the life of someone now your friend." Iron lungs in the hall or curtains drawn around a bed or respirator in the ward were also signs that someone had died. Kathryn Black discovered that "for those in iron lungs, the death signal was the passing of a nurse down the row of tanks, turning each mirror so the patients couldn't watch while a body was wheeled out in a now silent machine." (46). *Living with Polio*.

²⁷ Axtell, Agnes V. *A Polio Memoir*. Airleaf: 2004.

²⁸ Mark O'Brien with Gillian Kendall, *How I Became a Human Being: A Disabled Man's Quest for Independence*, Madison: University of Wisconsin Press, 2003.

²⁹ Shreve, Susan Richards. *Warm Springs: Traces of a Childhood at FDR's Polio Haven*. New York: Houghton Mifflin, 2007. "You screamed all night," Sandy Newcombe was saying. "I mean these long screams, and we were lying in bed, all of us listening for you to take a breath, and the scream just went on and on."

I looked over at the place where my mother should be, the chair next to my bed, and no one was there, only a sliver of Sandy Newcombe's face straight on me.

"It must hurt something terrible," Sandy said. "Does it hurt a lot?"

I didn't answer.

"We thought you'd died when you didn't take a breath." ...Later, the ward hushed with girls' whispering, I felt her hand over my forehead, her fingertips on my cheeks.

[Goes on to discuss revisiting this family calamity in nineteen fifty-one many many years later when her mother was dying]. Susan Richmonds Shreve, *Warm Springs*.

³⁰ Mason was in Morganton in September 1948. Incidentally, she was one of the people who spent the longest time in an iron lung. Mason, "The noise of children crying and nurses talking kept me awake. Sometime far into the night I must have fallen asleep from exhaustion and illness—and pills in little paper cups." Martha Mason. *Breath: A Lifetime in the Rhythm of an Iron Lung: A Memoir*. New York: Bloomsbury, 2003.

³¹ These communities included schools, sometimes vocational training, and strong social networks. Shell notes that these residential polio institutions have largely been excluded from the history of rehabilitation and from disability history. The American polio wards brought together polios from various economic classes. Friendships were formed in those communities, even in the huge iron lung wards housing dozens of patients. Personal accounts bespeak a group spirit resembling that of wartime platoon narratives. See Shell, p. 119.

positive: community. "wartime accounts"—differential bonding experiences over trauma than in some experiences.

³² Peg Kehret, *Small Steps: The Year I got Polio*. Chicago: Albert Whitman and Company, 1996. Shirley said, "I miss my grandma. When I was little, she used to sing me to sleep."

Alice said, "I'll sing you to sleep," and she began to sing, "Rock-a-bye, baby, on the tree top."

This was the first time I had heard Alice sing; she had a clear, strong soprano voice. After listening to Alice's song, nobody said another word. We didn't want to break the mood of her lullaby.

The next night after lights out, I said, "Alice, I know how to harmonize. If you'll sing soprano on some songs, I'll sing alto."

Alice sang: "Shine on, shine on harvest moon, up in the sky."

I chimed in with the harmony. "I ain't had no lovin' since January, February, June or July."

Dorothy giggled at the lyrics. Alice and I sang on.

My mother's family used to go on picnics, and as dusk fell, all the aunts, uncles, and cousins would sit around the campfire, singing. Mother always sang as she worked around the house, too, and when I was small, she often sang songs to entertain me. Whenever my family traveled, we sang in the car as a way to pass the time. Because music had always been part of my life, I knew all the words to many songs.

Alice, whose main source of entertainment for years was listening to the radio, knew many songs, too.

Dorothy and Renée also loved to sing. Because Shirley's breathing was shallow, the rest of us couldn't hear her sing, but she said she liked to try.

From then on, every night after lights out, we all sang in the dark. We sang "Blue Skies" and "I've Been Workin' on the Railroad" and "You Are My Sunshine." We sang rounds: "Row, Row, Row Your Boat" and "Three Blind Mice."

One night we sang longer than usual, doing all of our favorite songs and thinking of new ones that we hadn't done before. After more than an hour of this, Dorothy remarked, "I'm hungry."Thanks to all those songs in the dark, my singing voice was improved, even though I now used my stomach muscles rather than my diaphragm.

³³ Tuskegee, AL is about 1.5 hours away from Warm Springs.

³⁴ This was typically done by Fred Botts, Warm Springs Business Manager. Botts had trained as an opera singer.

All from Gould:

Basil O'Connor meets Roosevelt in 1925. O'Connor had been a relatively poor Irish Catholic growing up—he supported himself through Dartmouth College by playing the violin in a dance band he had organized (Gould, p. 44. Quote is from NY times, 10 March 1972).

Fred Botts, an early arrival at Warm Springs, was an aspiring opera singer, a victim of the 1916 epidemic. For info on Botts, see Roosevelt Warm Springs Institution for Rehabilitation Library.

After FDR won the governorship of NY he came to Warm Springs on Thanksgiving (which would thereafter be known as founder's day). After turkey at dinner, Fred Bott, this time "dressed up in an outrageous minstrel costume," sang humorous songs. Cited from Turnley Walker, *Roosevelt and the Fight Against Polio*. P. 144.

July 1931 is first publication of *Polio Chronicle* magazine put out by patients at staff at Warm Springs.

³⁵ Clara Yelder, who was hospitalized in the all-black Infantile Paralysis Center in Tuskegee, Alabama, remember that they passed the time by talking and that eventually they "had a radio. The center of our day was listening to the radio. There were no televisions."

³⁶ Charles Andrews notes writing a song for his son that would play for him over a broadcast—so that he could hear it in his hospital room. In the same book, there are notes a disc jockey named Cactus Jack who dedicated records to the two lung patients every day. Also: The nurses seized upon the radio as a new-found opportunity to promote the intake of food. While he listened raptly to music, these two schemers stood by quietly shoveling mouthfuls of gelatin, custards, and strained baby foods down his gullet. *No Time for Tears* Chapter X.

³⁷ While at the hospital, children were “prescribed a program of ‘wholesome’ activities such as good music, books (not comics), movies (excellent nature movies, rather than cartoons, which were too exciting and stimulating”) and various creative activities. See Mary T. Westbrook, “Early Memories of Having Polio: Survivors Memories versus the Official Myths”

³⁸ Martha Mason. *Breath: A Lifetime in the Rhythm of an Iron Lung: A Memoir*. New York: Bloomsbury, 2003.

Mrs. Lee told me stories about composers and identified different instruments as we listened to symphonies. She helped me hear themes and variations on themes in symphonies and chamber music. "Remember," she said as we listened to Beethoven, "the Fifth speaks its own name. It introduces itself to you. This is the Fifth." She taught me how to seat an orchestra and the difference between a French horn and an English horn. In my mind I waltzed to Strauss and Chopin. Bach lifted my soul to the heavens, freeing me from the mundane world. Wagner painted my spirit on an imaginary canvas with heavy strokes; Schubert feathered in a spirit of light. Mozart twisted my inner being into deepest pain or highest happiness as easily as a baker shapes his dough into different breads.

"Have you ever listened to an opera?" Mrs. Lee asked me one morning.

"No," I admitted.

"Today is a good time to fill that chasm in your mind. Today is Saturday. Therefore, it's Texaco-Metropolitan Day. Have you. ..."

"Wait! Wait. I don't know chasm."

"Oh, sorry. Do you know what a ravine is?"

"I think it's like a gully, but I'm not sure." I treasured every new word I learned. Mrs. Lee seemed to know every single one in Webster's dictionary.

"Another one you may want to lock in your treasury is abyss, which is also chasm, gully, hole, gorge, cavity, etc. Abyss is spelled a-b-y-s-s. Okay?" She watched me nod my head.

"Where was I? Yes, yes, our opera matinee. We're in luck. You, my young friend, will enter opera with *Madame Butterfly* as your hostess. Operas are plays—much like the Shakespeare you like so much—but set to music. Like Shakespeare's plays, operas can be tragic, opera seria, or comic, buffa, later opera comique. In Shakespeare the words are beautiful on their own.

In opera the words are spoken and sung. The singing is more important than the words. Opera stars have magnificent voices. Arias were written to showcase a particular diva, first lady of the opera scene at that moment. These singers are actors, too, but more singer than actor. They do incredible things with the same vocal equipment we have. The music overrides the story to the point that most people—including me—know Puccini wrote it, but most of us don't remember who wrote the words. I'll fill you in on the story, also called the libretto. The major songs, solos, in an opera are called arias. Let's take a break."

After thirty minutes or so of complete silence with her eyes closed, Mrs. Lee, refreshed and ready to continue, said, "Now, let me tell you about *Butterfly*." As she recounted the story of the young Japanese woman's passion for Pinkerton and his desertion of her, I was touched that she chose to die with honor rather than live in disgrace and that she used her father's dagger to kill herself. The concepts of Oriental culture invoked another lesson for another day.

But that day was for opera. As we listened to the broadcast, I felt the joy of Cio-Cio-San when she was loved and her agony when she was abandoned. Even though I did not always understand what was going on, I was deeply moved, especially by *Butterfly's* soul-wrenching aria at the end.

³⁹ " believe if you can keep a reasonably attainable goal always in front of a handicapped child, he will strive to reach it. We have started Chuck on his piano lessons again, and by prearrangement his teacher is gentle yet firm. It is difficult for him to get his left arm up to the keys, but his fingers all manipulate. Once he has swung the arm up to the keyboard, he slides the fingers around from note to note and hunches up his shoulder muscles to lift the arm for big jumps. In just three months of this we have detected considerable improvement in his forearm control and finger dexterity. At first he was reluctant to start back, but now that he has mastered a number of simple pieces, he enjoys the piano again and is getting tremendous self-confidence from his ability to use the left arm a little." *No Time for Tears*, Chapter XX

⁴⁰ I didn't remember anything about my own polio, although I was told that I had been paralyzed, that the paralysis had lasted a few weeks, and that I had screamed in pain whenever someone got close. But to me it was as though I'd been born with a crippled leg. I didn't know how it felt to walk normally, so the trauma of paralysis was not a conscious memory. Susan Richmonds Shreve, *Warm Springs*.

⁴¹ Wilson notes the following: Drs. Howard Rusk and Henry Kessler and Dr. Harold Visotsky

⁴² Many polio survivors were "encouraged to forget their polio and put the past behind them." Sheer and Luborsky.

⁴³ Making up about two percent of cases of paralytic polio, bulbar polio occurs when poliovirus invades and destroys nerves within the bulbar region of the brain stem.[1] The bulbar region is a white matter pathway that connects the cerebral cortex to the brain stem. The destruction of these nerves weakens the muscles supplied by the cranial nerves, producing symptoms of encephalitis, and causes difficulty breathing, speaking and swallowing.[13] Critical nerves affected are the glossopharyngeal nerve (which partially controls swallowing and functions in the throat, tongue movement, and taste), the vagus nerve (which sends signals to the heart, intestines, and lungs), and the accessory nerve (which controls upper neck movement). Due to the effect on swallowing, secretions of mucus may build up in the airway, causing suffocation.[36] Other signs and symptoms include facial weakness (caused by destruction of the trigeminal nerve and facial nerve, which innervate the cheeks, tear ducts, gums, and muscles of the face, among other structures), double vision, difficulty in chewing, and abnormal respiratory rate, depth, and rhythm (which may lead to respiratory arrest). Pulmonary edema and shock are also possible and may be fatal.[42]

The bulb is an archaic term for the medulla oblongata.[1] In modern clinical usage, the word bulbar (as in bulbar palsy) is retained for terms that relate to the medulla oblongata, particularly in reference to medical conditions. The word bulbar can refer to the nerves and tracts connected to the medulla, and also by association to those muscles innervated, such as those of the tongue, pharynx and larynx.

⁴⁴ But while that raises the possibility of a direct link between polio itself and depression, nearly all people who had polio experienced traumatic separations from their families, along with the wounds—both physical and emotional—of subsequent surgeries, and the ongoing injury of finding themselves in severely constrained social roles. In addition the pressure on people who'd had polio to minimize the extent of their disability, to be cheerful overcomers, to fit themselves into the normal world, often resulted in a bifurcated self. Alongside the self who was competent, precociously mature, and strong, another, more shadowed self lived—sensitive to criticism, fearful of being unable to live up to the world's expectations, and above all, lonely, for this was the part of ourselves we were supposed to keep well hidden. Another near- perfect recipe for creating emotional distress.

Dr. David Bodian, a prominent polio researcher, wrote more than half a century ago: "All available evidence shows conclusively that every case of polio exhibits damage in the brain." What polio affected was not cognitive functioning, but the brain stem, which, in addition to regulating breathing and swallowing, also controls such higher-level functions as alertness and the sleep/wake cycle, as well as blood pressure, heart rate, and muscle tone. Most of us who had had polio didn't know anything about brain involvement until we began to hear about it, decades after our initial experience with the disease, as a possible cause of postpolio fatigue. ...Anne Finger, *Elegy for a Disease*

Bodian was involved in research that concluded that the poliovirus multiplied within parts of the brain as well as the spinal cord.

⁴⁵ Van der Kolk, *The Body Keeps the Score*, 80. Some of Van Der Kolk's work here builds on Pavlov's accidental discovery of the dogs who almost drowned and could not escape and were clearly traumatized. Van der Kolk tells the story of Stan and Ute earlier in the book, a married couple's whose drastically different reactions to a car accident led to completely different trauma reactions.

⁴⁶ Van der Kolk, *The Body Keeps the Score*, 81. Reciprocity is defined as being truly seen and heard by the people around us, feeling that we are held in someone else's mind and heart. For our physiology to calm down, heal, and grow we need a visceral feeling of safety.

⁴⁷ Anne Finger's explanation is interesting, as is her metaphor that "the body is not silent."

⁴⁸ Murakami captures in compelling imagery how trauma devastatingly disrupts the ordinary, average-everyday linearity and unity of temporality, the sense of stretching-along from the past to an open future (<https://www.routledge.com/products/9780881634679>). Experiences of emotional trauma become freeze-framed into an eternal present in which one remains forever trapped, or to which one is condemned to be perpetually returned by life's slings and arrows. In the region of trauma all duration or stretching along collapses, the traumatic past becomes present, and future loses all meaning other than endless repetition. Because trauma so profoundly modifies the universal or shared structure of temporality, the traumatized person quite literally lives in another kind of reality, an experiential world felt to be incommensurable with those of others. This felt incommensurability, in turn, contributes to the sense of alienation and estrangement from other human beings that typically haunts the traumatized person. Torn from the communal fabric of being-in-time, trauma remains insulated from human dialogue.

⁴⁹ quote is from Finger

⁵⁰ Quote from <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Post-Polio-Syndrome-Fact-Sheet>

⁵¹ Wilson.

⁵² Counts of the total number of polio survivors living in the US differ dramatically from one another. They range from a high of around two million (an estimate constructed in 1987, and sometimes incautiously repeated to this day²) down through approximately one million (an estimate usually constructed with data from 1994-1995, but also still floating around in some quarters as if it were current) and bottoming out at a presumably more current estimate of around 600,000, or perhaps 500,000. It is difficult, however, to get a clear idea of the reliability of these conflicting estimates, the methods used to construct them, and sometimes even the sources used for them. Article by Lawrence Becker, 2006: <http://www.polioplace.org/sites/default/files/files/PolioSurvivorsInTheUS1915-2000.pdf>

⁵³ Still this Johnson quote.