

Short greeting: content warnings for Medical contexts, diagnoses, and institutionalization
Medical racism
Family separation
Ableism and older constructions of disability, outdated language
Abuse

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 .

Anne Finger's narrative of her childhood conjures the complex cultural web around polio, from hospitalizations, forced family separations, and societal exclusion to silencing, denial, and memories (suppressed or painful). Like Finger, many polio survivors processed these experiences in a flood of narratives from the 1960s through today. Reading these accounts reveals how intensely 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. Weaving together testimonies of polio survivors, midcentury medical, psychological, and music therapy publications, media coverage and charity campaigns, this paper analyzes America's midcentury polio soundscapes were intimately connected with disability, healing, and trauma.

First, a few notes: this is work in progress on a larger project parsing intersections of music and sound with polio—from stories of musicians to music's role in fundraising for the vaccine.¹ I focus today on a single aspect, the soundscapes of mid-century American polio wards & medical institutions. I focus on the United States—primarily epidemics from the 1930s-50s—yet want to stress the importance and difference of polio epidemics in other places and eras.² A note on sources: in some cases, I draw on period medical discourse and archival material, but I concur with the work of Gracen Brilmyer and others who have noted the ways records and archives are often produced by those in power, erase or construct harmful stereotypes around disability, or cause trauma through erasure or archival absence itself.³ Most of this paper's source material, therefore, draws on hundreds of published narratives and oral histories from polio survivors.⁴ Centering *self*-representations, these sources also demonstrate vastly different experiences of polio based on nationality, age, race, class, gender, geography, etc.⁵

II.
Groundwork:
caveats &
scope,
sources,
disciplines

This project sits amidst disciplines, from musicology to music therapy, education, sound studies and crucially: critical disability studies and trauma studies.⁶ Polio survivors often had/have a fraught relationship with disability. Their narratives highlight how notions of “overcoming” and “emotional disavowal” permeated mid-century disability discourse. Indeed, their self-representations are at times *distinctly* at odds with contemporary disability models, requiring us to situate polio amidst its historical and social contexts⁷ and consider “suppressed ‘disability’ narratives” (borrowing Amy Wlodarski’s recent work on Holocaust testimonies).⁸ In seeking to understand polio’s (shifting) meanings, I find Alison Kafer’s “political/relational model of disability” useful, particularly how it embraces *both* social effects *and* “lived realities of impairment.”⁹ Like other critical disability thinkers, Kafer critiques the medical model’s “curative imaginary,” the toxic overemphasis on interventions.¹⁰ The inherent complexity of this political-relational model emerges in narratives by people with polio, who recount their encounters with institutional medicine both through stories of care and agency,¹¹ *and* immensely painful ¹² histories of medical incarceration, abuse, abandonment,¹³ eugenics, and racism.^{14,15}

Indeed, the polio epidemic also spawned a unique complex of traumas: 1) collective *cultural* traumas yet also intensely individual experiences often caused by or mediated within medical institutions. (Note: these traumas were frequently compounded by silencing: Marc Shell explicitly compares polio writing to Holocaust narratives.) Within these medicalized spaces, I consider not just how sound can be traumatic but also Jenny Johnson’s analyses of how traumatic memories can emerge *through* sound. As part of a larger critical reckoning of sound and music in medicalized institutions, I consider how embodied listening might function for polio survivors in particular.¹⁶

One thread that connects these topics is *time*. Kafer writes of “crip time” as “a challenge to normative and normalizing expectations of pace and scheduling,” a different imagined future.¹⁷ Foundational trauma scholars have likewise theorized time, from Cathy Caruth’s more ahistorical discussion of elisions between past, present, and future to Jenny Edkins’s “trauma time”—alteration of historical narrative linearity—to Dominic LaCapra’s historically grounded push for futurity to Marianne Hirsch’s work on “postmemory.”¹⁸ This project demonstrates how *polio*’s histories push against universalist concepts, revealing instead historically contingent experiences and understandings. Chronology is important, since many polio survivors experienced illness before the mainstream disability rights movement in the United States (though some early disability activists in fact had impairments from polio). Ultimately, I argue attending to this particular set of experiences at this historical moment offers essential new understandings of the connections between trauma, disability, sound, and music.

Turning now to today’s three case studies: I’ll commence with mid-century medicalized soundscapes in the thousands of polio wards and rehabilitation centers scattered across the country, then move on to the functions of music or “musicking” within these spaces, and conclude by exploring some complex relationships between music therapy & polio.

A. Ward Sounds

I begin with soundscapes of these medicalized spaces: many polio patients noted immobility (or polio itself) made them more attentive to sound. While in an El Paso hospital in 1952, for example, Bob Axtell noted “he developed an acute interest in whatever he could see and hear.” Conversely, Marc Shell recalled being “very sensitive to noise and need[ing] quiet.” As these two recollections emphasize, sound served as knowledge, comfort, safety, comfort, and

community as well as noise or traumatic memory. Sound was omnipresent, essential, and positional, interpreted via both normate discourse and a diverse variety of disabilist acoustemologies. Accounts of these midcentury medicalized soundscapes align with Ailsa Lipscombe's analyses in her recent work on sonic ecologies of the COVID-19 pandemic, where she stresses "the contradictory frames of interpretation that are used to decipher sounds" within medicalized spaces. By challenging notions of "ideal or normate sonic experiences" and emphasizing "attentive, subjective listening," Lipscombe offers "a model of medicalized listening that honors the potentials of sound and silence to both harm and heal."

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Sounds could be a source of love, or community. Writing of his time in an isolation ward in Elgin, Illinois in 1953, Charles Mee recalled straining to hear his mother's high-heeled shoes—this beloved sound, utterly distinct from other footfalls, was a longed-for signal that family was coming to visit. While memoirs note the "constant din" of voices and sounds in these medicalized spaces, they sometimes became expected or communal; Susan Richards Shreve wrote of being able to sleep through noise during her time at Warm Springs, and of the "hushed nocturnal whispering" as girls murmured to each other in the nighttime hours.

Sound could be a source of knowledge, or safety. The sound of respirators—including "iron lungs"—permeated certain wards; survivor and historian Daniel Wilson noted 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." These soundmarks were experienced in radically different ways: ableist public commentary (or memoirs by friends and family of polio victims) often emphasized the iron lung as an abject, horrible sound. Yet in memoirs by polio survivors, respirators—often described with powerfully onomatopoeic language as booming, wheezing,

whooshing—were rhythmic, sonic epistemology, offering knowledge about your own body or knowledge about your friends nearby. 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.” Silence—such as in the case of a power outage—could be terrifying or deadly. Being able to produce sound, in fact, could save your life—some polio survivors with speech impairments developed a system of whistles and clicks to alert medical personnel of their needs.

Click

Medicalized sounds could also be traumatic. Anne Finger, writing of her surgery in Utica Children’s Hospital in central New York, 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 stresses her disablist hearing, noting that while these might be “ordinary” or quotidian sounds for the nurse, they terrified her because of their familiarity in painful or traumatic experiences. Even in other contexts, soundmarks could evoke traumatic memories. Finger vividly recalled hydrotherapy—the echoing of voices, the sloshing, the clanking of weights—and felt a “sense of familiarity and shock” when she heard those precise sounds again decades later in a film about wounded Vietnam war veterans. As Lipscombe concluded in her study of later medicalized sounds, “diverse bodies listen in diverse ways, and sonic cues take on distinct affective resonances in response to embodied and temporal interpretive frames.” Sound mattered in the experience of polio, but straddled a variety of normate, disablist, healing, and traumatic understandings.

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B. Musicking in Medicalized Spaces

The wards also reverberated with *musicking communities*, spaces for therapeutic communal music-making and listening.¹⁹ Singing—informal, improvised, participatory—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 lullabies, rounds, campfire songs, and top radio hits, harmonizing with her wardmates Shirley and Alice.²⁰

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Some of the most beloved sounds came from radios, a cherished commodity. Many narratives recall the day a radio arrived on the ward (or was received as a gift from a departing patient).²¹ There are occasional grumbles about lack of agency—being forced to listen to the programs your ward mate liked!—but most narratives recall immense pleasure in listening. Radios also sutured separations; local DJs dedicated songs to polio patients, and Charles Andrews recalls writing a song for his son, which via the local radio station resounded into the boy's hospital bedroom.²² Sometimes radio served as therapeutic adjunct; one polio patient remembered nurses found it easier to administer meals and treatment while he relaxed and listened to the radio. Yet radio listening intersected with problematic uplift rhetoric, as polio patients were exhorted they would recover more thoroughly if they listened to “good music.”²³²⁴ Writing of her stay in the Asheville Orthopedic Hospital in 1948, Martha Mason details a quasi-“music appreciation” course from her wardmate Mary Johnston Clark Lee, who tutored her in listening to Beethoven and quizzed her after Saturdays sessions with the Metropolitan opera broadcasts.²⁵

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As one particular case study, the archives for the polio hospital and rehabilitation center in Warm Springs, Georgia testify to a rich mid-century musical culture. Residents listened to radio programs and concerts from visiting stars or locally hired musicians, took part in bands,

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orchestras, choirs, plays, even a “Poliopolitan Opera Company.” Informal sing-alongs took place around the piano, but more formalized concert-giving dotted the yearly social calendar as well.

Song sheets demonstrate a thriving culture of locally specific contrafactum.²⁶ I’ve

examined about 75 of these contrafacts from the 1950s, most with lyrics written by patients (occasionally some by medical personnel).²⁷ The lyrics resonate with inside jokes—naming specific Warm Springs doctors, physios, or campus buildings—and daily conditions, such as impatiently awaiting mail from home.²⁸ Humor and satire abounds, often in reference to medical treatments and devices: “Blount Frames,” corsets, braces, surgery, hot packs, hydrotherapy, and pervasive puns about body parts (particularly “gluteus maximus”).²⁹ Many songs concern dating and romance: sneaking out after curfew, hooking up by “bush 13” (apparently the prime necking location), sometimes with pointed commentary on the intersection of romance with polio.³⁰ The contrafact source melodies encompass a wide variety of musical genres, from folk music and campfire songs to show tunes, early 20th century pop songs, and western swing and honky tonk, with some clearly designed for call & response performance contexts.³¹

There is a “songwriting contest” mentioned with Songsheet #1. Some songs may have been written by medical personnel at the Institute rather than patients (possible with “I’ve Been Working on the Railroad,” “Clementine,” “Winter Wonderland,” “Daisy, Daisy”).

The Warm Springs archives also reveal more harmful musical stories, intersections of medical and musical racism. Warm Springs was for white polio patients *only* until the mid-20th century (both the NAACP and National Urban League reconsidered involvement in FDR’s birthday balls as a protest over Warm Springs’ segregation policies, as Naomi Rogers has analyzed in her pivotal work on the the medical racism of polio).³² Ultimately, the Tuskegee Institute opened the Tuskegee Infantile Paralysis Center in 1941 about 1.5 hours away, which had much less funding available for elaborate music-making, testifying to what Zosha Stuckey has analyzed as the massively unequal “conditions of confinement” between Black and 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).

facilities.³³ Moreover, archival materials from Warm Springs detail local African-American musicians performing for the all-white patients, Warm Springs administrators giving blackface performances, and you may have noticed that many minstrel songs appear in the contrafactum collections.³⁴ Therefore, much as music was a source of community and solace at Warm Springs, it was also used to reinscribe racial hierarchies, demonstrating a kind of harmony between medical and musical racism.

Slide 13 C. Music Therapies? [and Music Education]

The explosion of polio epidemics in mid-century America overlapped precisely with the professionalization of music therapy as a discipline in the West.³⁵³⁶ In this capsule timeline,

Slide 14 you'll note burgeoning initiatives from the late 1930s-50s, at the intersection of Depression-era government funding & wartime needs and operating under the aegis of the Veterans Administration, the US military, and the Music Teachers National Association.³⁷³⁸ Much of this was categorized as "hospital music"—a central institutional setting for early music therapy. This image from the September 1949 Hospital Music Newsletter features a diagrammatic explanation of various uses of music in hospitals, from recreation and entertainment to instruction, medical request, special projects to physical reconditioning.

I've analyzed reports from dozens of institutions in the US and Canada where music was used with polio patients (in hospitals, acute care facilities, private schools for children with disabilities, & large public school districts such as Chicago). Therapeutic methods of the 1950s often rely on behaviorist impetus and radically different methodologies than the music therapy approaches that would arise during the 1970s, and are rife with intensely problematic treatment

Today,
better
music
therapies
tend to
focus on
relation &
consent
& co-
creation

of disability.³⁹ Generally speaking, there is an overemphasis on prescriptive and ableist ideas of cures and “improvement.”⁴⁰

In these accounts, there are frequent references to rhythm games, rhythmic movement, rhythm instruments, rhythm band;⁴¹ there is an entire separate study to be done here on dance therapies, including the important role of Irmgard Bartenieff (who used Laban-style movements as polio therapy). Anecdotes recount instrumental choices tailored to specific disabilities; a polio survivor with a left hand impairment might play baritone horn, a survivor with leg paralysis might play the violin, patients with paralysis in other parts of the body might be directed to play the mouth organ, etc. Other discussions center on “co-playing,” where survivors might collaboratively play a single instrument, using their own particular strengths.

Yet the lion’s share of commentary on specific musical instruments focuses on using the piano as a therapeutic tool (maybe 1/3 of accounts I’ve read focus on piano). To give two examples: 1) in 1955 Barbara Denenholz at NYU’s Bellevue Institute of Physical Medicine and Rehabilitation engaged in a project with multiple children, including a 15-year polio survivor named Evelyn.⁴² Assessing Evelyn as having impairments in her arm, shoulder, and right leg muscles, the therapist chose specific selections of music aimed at increasing endurance and range of motion. A list of ten selections is noted in the report, ⁴³ chosen for wide intervals, chords, arpeggios, liberal amounts of passagework, 4 octave scales, etc. 2) a 1951 study by Charlotte Brim aimed to increase respiration amongst post-respirator patients at the James Whitcomb Riley Hospital for Children in Indiana.⁴⁴ Brim curated songs to increase respiration amongst her cohort (see the list she appends), with up to 125 songs selected for rhythmical interest, sustained tones, etc.

In the sources I've analyzed, music therapy for polio survivors had multiple goals: emotional release; confidence building; increasing energy or endurance; and, frequently, "music as physical control." Other ideologies lurked within these projects as well. In a 1961 discussion of a 12-year old post-polio survivor learning the piano, the study's author described music as an initial step towards manual housework such as ironing.⁴⁵ In the case of Evelyn, the music therapist notes the "prescription" was to **"launch [Evelyn's] real and lasting interest"** in music, adding that after just a few weeks of therapy, she was now considering a career as a music educator. In her study of childhood singing, Brim aspired to education and appreciation/psychology. Mid-century music therapy projects entangled polio patients with all sorts of messy ideas about cultural uplift, expectations about gender and race, "curative" imaginaries, etc. In his work on music therapy pioneer Willem Van de Wall, J. Martin Vest has elucidated the "carceral" origins of music therapy and uses of music therapy as social control and embodied *discipline*, reminding us early music therapies often intersected in painful ways with institutional medical ideologies.⁴⁶

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Reading these narratives, it is abundantly clear mid-century polio practices spawned a particular complex of sound and music, experiences that played a critical role for healing, community, and solace AND discipline, control, and trauma.⁴⁷ Stored in the body, in so many senses, sounds and memories of the "polio era" are still with us amidst individuals impacted by this epidemic, not in the least as many polio survivors process trauma *and* navigate post-polio syndrome. Moreover, we might consider what this era could teach us about music & sound in our present and future epidemics.⁴⁸⁴⁹

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 Gracen Mikus Brilmyer, "I'm also prepared to not find me. It's great when I do, but it doesn't hurt if I don't:" crip time and anticipatory erasure for disabled archive users." *Archival Science* 22 (2022): 167-188. "Many scholars in the field of disability studies have used records to illuminate pieces of disability history by exploring how disabled people have been historically documented for their deviance from "the norm" as well as addressing the scarcity of records (or difficulty in finding records) around disability....records produced around disability can create, represent, and/or reinforce harmful stereotypes around disability. While not the only documents on disability, these types of historical records are often produced by those in power, and the voices of those whose lives were affected by such representations are often missing from records" (169).

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. 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."

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.

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.

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.

his 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.

⁶ Critical disability studies is an interdisciplinary field that examines the social, cultural, and political experiences of people with disabilities. It challenges ableist assumptions and seeks to empower individuals and communities.

⁷ 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

⁸ Wlodarski’s work is specifically in relation to Holocaust narratives, but is also relevant in the work of disability narratives.

⁹ Alison Kafer, *Feminist, Crip, Queer* (IUP, 2013). She adds that “At the same time, the social model with its impairment/disability distinction erases the lived realities of impairment; in its well-intentioned focus on the disabling effects of society, it overlooks the often-disabling effects of our bodies. People with chronic illness, pain, and fatigue have been among the most critical of this aspect of the social model, rightly noting that social and structural changes will do little to make one's joints stop aching or to alleviate back pain. Nor will changes in architecture and attitude heal diabetes or cancer or fatigue. Focusing exclusively on disabling barriers, as a strict social model seems to do, renders pain and fatigue irrelevant to the project of disability politics.

As a result, the social model can marginalize those disabled people who are interested in medical interventions or cures. In a complete reversal of the individual/medical model, which imagines individual cure as the desired future for disability, a strict social model completely casts cure out of our imagined futures; cure becomes the future no self-respecting disability activist or scholar wants. In other words, because we are so often confronted with the medical framing of disability as unending burden, or as a permanent drag on one's quality of life, disability rights activists and scholars tend to deny our own feelings of pain or depression; admitting to struggling with our impairments or to wanting a cure for them is seen as accepting the very framings we are fighting against, giving fodder to the enemy, so to speak. But by positioning ourselves only in opposition to the futures imagined through the medical model, and shutting down communication and critique around vital issues, we limit the discourses at our disposal. As Liz Crow warns, in refusing to acknowledge pain, fatigue, or depression, “our collective ability to conceive of, and achieve, a world which does not disable is diminished.” Finally, drawing a hard line between impairment and disability, and having this distinction serve as the foundation for theorizing disability, makes it difficult to explore the ways in which notions of disability and able-bodiedness affect everyone, not just people with impairments. She argues for the political, and the concept of disability as experienced in and through relationships.

¹⁰ Kafer, *Feminist, Queer, Crip*, Chapter 1, page 4.

Medical model of disability—seeing disability as illness or disorder rather than difference. Not all looking for a diagnosis or cure.

“The medical model of disability, in which people are cast as outliers, requiring either rehabilitation by medical science or elimination by eugenics.” Howe, Blake, Stephanie Jenson-Moulton, Neil Lerner, Joseph Straus, *The Oxford Handbook of Music & Disability Studies* (Oxford: Oxford UP, 2016). Also notes medical models themselves are historically contingent. Also, that many of these essays chart and celebrate a countervailing trend toward disability communities formed, in part, around music making, which becomes an important mode for self-expression and self-representation.”

¹¹ Maler's article, for instance, gives some examples of how schools for the Deaf in the United States which employed Deaf teachers used music to evoke pleasure and satisfaction in schools. “Singing and signing of hymns, solo performances on musical instruments, and performances by deaf bands are all discussed.” See Maler, p. 197.

¹² See Braddock, David L. and Susan L. Parish, “An Institutional History of Disability.” In *Handbook of Disability Studies*, ed. Gary L. Albrecht, Katherine Seelman, Michael Bury. London: Sage Publications, 2001.

¹³ Rosenblatt, Adam. “Autism, Advocacy Organizations, and Past Injustice.” *Disability Studies Quarterly* 38, no. 4 (2018).

¹⁴ Martin Summers, on eugenic readings of neglect of communities as generational biological and racial inferiority. See Stuckey, "Race, Apology."

Medicalized institutions massively expanded throughout the 19th and 20th centuries, spawning the important activist and legal achievements of the 1970s

¹⁵ Often several events heralded as important here: 1971 Intermediate Care facilities program as Title XIX of Medicaid, right to treatment ruling in 1972, 1973 passage of the Rehabilitation Act, 1975 passage of Education of all Handicapped Children Act (IDEA) and then ADA in 1990.

Are we in a "post-institutional era"? Rosenblatt, Adam. "Autism, Advocacy Organizations, and Past Injustice." *Disability Studies Quarterly* 38, no. 4 (2018).

¹⁶ Anne Finger's explanation is interesting, as is her metaphor that "the body is not silent."

Johnson: 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.

While far from conclusive, Polio's unique impacts on the body could intensify trauma as well, by impacting nerve cells in the bulbar region of the brain or altering operations of the vagus nerve & impacting the visceral experience of the body to regulate safety and danger.

Interactions of the body and mind might have specific ramifications for some polio survivors. In *The Body Keeps the Score*, Bessel van 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. 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." 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. Polio therefore, at least for some, seems particularly likely to cause and intensify trauma through these brain-body-societal connections.

Always important to think what *kinds* of institutions: private, public, charity; where (what state of country); *who* is there (children, adults, etc?); specializing in what kind of disability (mental health treated very very differently from physical disabilities versus intellectual disabilities); when (what era); how long patients were in the institution, etc etc.

Stuckey, Zosha. "Race, Apology, and Public Memory at Maryland's Hospital for the 'Negro' Insane." *Disability Studies Quarterly* 37, no. 1 (Winter 2017).

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.

¹⁷ Kafer talks about temporal categories in framings of disability (chronic, intermittent, constant, etc—more medical model); disability studies turns this to “temporarily able-bodied.” She pulls from Irv Zola and Carol Gill as crip time as an in-group conversation, flexible standards, extra time needed. Curative temporality often comes with notions of “when will you be cured,” medical model. Notions of the future often having been used against disabled people.

¹⁸ Edkin’s study focuses on these questions in the realm of the political and the state. See “Remembering Relationality: Trauma Time and Politics,” in Duncan Bell, ed. *Memory, Trauma, and World Politics: Reflections on the relationship between Past and Present* (London, 2006) and Edkins, *Memory and Politics*.

For Caruth, see *Trauma: Explorations in Memory* (1995), Dominick LaCapra, *History in Transit* (2004), cited in Bond and Craps, *Trauma*, 78-81. See also Hirsch, *Family Frames*, 1997.

¹⁹ 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.

²⁰ 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.

²¹ 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.”

²² 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.

²³ 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”

²⁴ 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.

²⁵ “ 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

²⁶ It seems like ongoing repertoires and changes—for example, song sheets #3 and #12 contain some of the exact same songs, but also new ones, suggesting generations of repeated songs but also ongoing practice.

²⁷ There is a “songwriting contest” mentioned with Songsheet #1. Some songs may have been written by medical personnel at the Institute rather than patients (possible with “I’ve Been Working on the Railroad,” “Clementine,” “Winter Wonderland,” “Daisy, Daisy”).

²⁸ Locally specific references—names of Warm Springs doctors or physios or particular the specific buildings Note of locally specific references (Dr. Irwin, Dr. Bennett) and Mr. Botts (In the Evening by the Moonlight) and Georgia Hall (“Doin what comes naturally” and “Alma MAtter”) and “Miss Zuber” and “the Playhouse” turns the lights out (“Dew Dew Dewy Day”) and Dr. Hoke in “I Got Paral” and “Warm Springs Blues” and the “Medical Building” in She’ll be Comin’ ‘Round the Mountain” and “Rita” in “Winter Wonderland” and Dr. B in “Daisy, Daisy.” F.D.R. is mentioned in “Smiles.” The contrafact to “May the Good Lord Bless and Keep You” is specifically rosy about the Warm Springs family, noting a hilltop green with pine trees, the walking court in sunshine, laughter in the hall. Some patient concerns: waiting for mail and packages in “Alice Blue Gown.”

²⁹ Sometimes some real singling out of body parts: deltoids and pectorals in “I Got a Gal” or gluteus maximus in “Alma Mater” and glutei, deltoids, mastoids, in “From the top of your head” and gluteus maximus in “Daisy Daisy.” Some satirical or parodic tunes with sharp messages about “normals” and “staring” (“The Lady is a Tramp”). Sometimes some improvement or uplift rhetoric (as with the Humoresque song). One mentions fundraising—dimes and research will someday make polio go away (“Thanks for the Memories”).

³⁰ Note of dating culture (“These Blount frames,” “Po’leo”) and sneaking out after curfew and hugging/etc “back of bush thirteen” (“Meet me in St. Louis”; In the evening by the moonlight also specifically mentions bush thirteen and is a pretty racy courting song); “Shine ON, Harvet Moon” is about amorousness-wanting to spoon, having lost months of wooing time. “Divorce Me C.O.D. is a really interesting amorous example: talks about the misapprehension of not being glamour girls, but actually “when we go out on a date, invited to a dance, while the other girls jitterbug, we sit it out and romance. Mentions being carried over the threshold as a bride, and that by June 1st we’ll be altar bound.” In “Thanks for the Memories,” notes maybe some male members leaving soon that it’s a class of just one sex.

³¹ Some obviously call and response (a la campfire songs), such as “You Can’t Go to Heaven.”

³² 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.

³³ Tuskegee, AL is about 1.5 hours away from Warm Springs. In order to understand the extent of racism in Crownsville's earlier years, I will take into account 14 categories within conditions of confinement from 1921-1928 and compare them to the nearby, white asylum.

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 Oxford Handbook of Music therapy defines music therapy as a relational therapy involving the use of music in therapeutic processes with individuals and groups by a qualified practitioner who has undertaken appropriate training and undertakes ongoing professional development. Can often be difficult to explain and define because it is highly dependent on context of practice and needs of people. Bruscia defined music therapy as "a systematic process of intervention wherein the therapist helps the client to promote health, using music experiences and the relationships that develop through them as dynamic forces of change." World Federation of Music Therapy has defined music therapy as follows: "The professional use of music and its elements as an intervention in medical, educational, and everyday environments with individuals, groups, families, or communities who seek to optimize their quality of life and improve their physical, social, communicative, emotional, intellectual, and spiritual health and wellbeing. Research, practice, education, and clinical training in music therapy are based on professional standards according to cultural, social, and political contexts." Sometimes some concern over the word intervention [shows the desire for change, but respect is needed in that process—therapeutic practice is active rather than benign].

frames this as 5 constructs:

Contexts and populations: contexts are the situations in which therapy is provided (such as community day program or hospital), some populations are diverse (special school with students with range of needs) versus highly specialized (neonatal intensive care unit).

Music therapy models and approaches: methods and techniques sometimes specific to music therapy [Nordoff-Robbins] or overlaid across a model from another area, such as Developmental Music therapy. Four approaches: Nordoff-Robbins founded providing music sessions in special educational services in 1960s and 1970s in England. Feminist perspectives: concerned with power in social and political domains, hoping to enable emancipation.

Carolyn Kenny's Field of play, also well known in Indigenous studies. Asks therapists to suspend their judgment. Community music therapy: resists definition, but perhaps encourages musical participation and social inclusion, equitable access to resources, collaborative efforts for health and wellbeing in contemporary societies.

Music therapy methods: music can be co-created, or solo music making while other listens. Improvisations, or known songs sung together, music soundscapes developed for stories. Technology used. Four categories: improvisation, re-creation, composition, receptive.

Research: randomized control trial, case study, qualitative method studies, mixed methods. Must have ethical clearance from statutory body.

Training and Professional Issues: relatively few studies of music therapists professional experiences. Training highly context specific.

Edward, Jane, ed. *Oxford Handbook of Music Therapy*. Oxford UP, 2016.

³⁶ There were lots of developments in army hospitals in WWII. Need for training pioneered setting up a 4-year degree in training musicians for this sort of service at Michigan State College in 1944. 1946 a training course was established at Chicago Musical College with internship at Downey Veterans Administration Hospital. University of Kansas has a Master's in Music Ed with internship at Topeka State and at Winter Va. A;lvorno College of Music in Milwaukee. College of the Pacific. Fontbonne in St. Louis. Describes this as the growth of "hospital music". Notes greatest field to date has developed in mental hospitals, but the needs of handicapped children should also be recognized.

³⁷ Vest calls this period post WWII as a rapidly growing cohort of full-time music therapists. “Prescribing Sound.”

³⁸ I have not looked at this, but would like to: Ruth Boxberger, “A Historical Study of the National Association for Music Therapy” (Ph.D. diss, University of Kansas, 1963).

³⁹ Vest explains this impetus towards “medical” and behaviorist approaches in the 1950s (lots of “research,” “science” and recorded music) and notes that this is all quite different from 1970s developments (Bonny, Guided Imagery and Music) or Priestly/Tyson (more psychological approaches). See Vest, “Prescribing Sound.”

⁴⁰ As one example: Margaret Zattau Roan, “Music to Aid the Handicapped Child,” (she was a music therapist at the Marian Howard School for Exceptional Children, Private Studio for Music therapy students on medical referrals, chairman of music in government hospitals, based in Georgia). “The cerebral palsied child is injured in the brain, at the ‘know-how’ level, while the polio injury is in the muscles themselves.” See the Book of Proceedings for the National Association for Music Therapy, Volume I (1951). Esther Goetz Gilliland, ed. Chicago, Illinois: National Association for Music Therapy, 1952. <https://archives.mountainscholar.org/digital/collection/p17393coll72/id/6419/rec/91>

some undergrad ideas, summarize:

A common belief within both the non-disabled and disabled communities is the concept of a hierarchy of disability. Disability hierarchies position certain impairments as more or less disabling than others, with the idea that some impairments are “better” or less severe than others. The fact that many disabled people believe in a hierarchy of disability only perpetuates the social exclusion and stigma felt by all persons with disabilities. Disabled people might not know they discriminate against or degrade others with disabilities, but it still occurs, often in forms not easy to recognize. Disability hierarchies are understood as the idea that some impairments are positioned as “worse” or more severe than others, and thus more deserving of stigma. One of the greatest achievements of the disability movement, and disability studies, has been to explore both the commonalities and differences which exist among people with disabilities – not to determine who is deserving of the most respect, but to examine how processes of stigma and disrespect create hierarchies of shame and privilege that injure all disabled people. The most problematic element of Hockenberry’s writing is that he does not promote a message of universal dignity and respect. It is precisely the idea that there are some people who are “really disabled” and others who are not, which leads to social hierarchies between disabled people. Through this discourse, some disabilities become acceptable, while others remain highly stigmatized and are subject to social exclusion. Unfortunately, this argument also seems to imply that people who are “really disabled” somehow deserve the lack of rights and disrespect which they receive. After all, they are “really disabled” and therefore it may be impossible for them to have social inclusion. This message is antithetical to the foundational principles of the disability movement. Dividing people with disabilities according to who is “really disabled” and who is “not really disabled” also diverts attention from the stigma, prejudice and inaccessible resources that we all share in common. Whether the barriers are attitudinal or physical, the disability movement has challenged practices of social exclusion by promoting alternative messages of inclusion based on respect for diversity.

⁴¹ Note there is probably more research to be done on this, but Willem Van de Wall in the 1930s apparently utilized a “rhythm orchestra” with [giant scare quotes] the “mentally deficient.” The orchestra included cymbals, triangles, tambourines, drums, and other non-pitched instruments. See J. Martin Vest, “Prescribing Sound: Willem Van de Wall and the Carceral Origins of American Music Therapy.” *Modern American History* 3 (2020): 109-132.

⁴² Barbara Denenholz (Musicians’ Emergency Fund, New York City), “Music Therapy with Handicapped Children at the Institute of Physical Medicine and Rehabilitation: A Demonstration.” *Book of Proceedings for the National Association for Music Therapy, Volume IV (1954)*. Papers from the Fifth Annual Convention, E. Thayer Gaston, ed. Lawrence, KS: Published National Association of Music Therapy, 1955.

⁴³ In his discussion of Willem Van de Wall, Vest notes that repertoire mattered. Van de Wall had a lot of opinions about folk music vs. art music versus jazz. See Vest, “Prescribing Sound.” I have certainly noticed a predominance of certain genres in these kinds of projects. Vest also discusses how Van de Wall prescribed musical examples based on racial identity for patients. “racial stimuli” in his musical selections. In the case of Evelyn, while we know that Evelyn had 100 music sessions, it’s not clear how long the sessions were or how long each piece was used.

⁴⁴ Brim actually refers to this as “vital capacity” (number of cubic inches of air a person can forcibly expire after the deepest inspiration possible). In terms of some specifics, the class met for 30 minutes 5 days a week, and included all of the post-respirator poliomyelitis patients of kindergarten and school age (plus two adults who asked to join). There were 44 patients during the year (enrollment varied from 17-29). Some remained for the entire year, a few are still attending, some passed away after their stay. There was a lot of scientific measuring of respiration during the study (intending to find increase in cc of respiration over the course of the study). Brim, Charlotte L. “Music, Vital Capacity, and Post-Respirator Patients.” *Music Educators Journal* 37, no. 3 (Jan 1951): 18-19.

⁴⁵ See the Book of Proceedings for the National Association for Music Therapy, Volume VX (1960). Papers from the Eleventh Annual Convention, Erwin H. Schneider, ed. Lawrence, KS: Published National Association of Music Therapy, 1961.

1. MUSIC THERAPY WITH CERTAIN PHYSICALLY HANDICAPPED CHILDREN
SISTER M, JOSEPHA.

⁴⁶ Vest analyzes Willem Van de Waal’s use of music as social control (or “as tool of discipline”), using communal singing to forcefully change the mood/affect of people in institutions (Vest traces how this morphs into Ira Altschuler’s ISO Principle, where music has to match the mental state and then change in an attempt to manipulate his or her behavior, which basically permeated the field well into the 1990s). Vest, “Prescribing Sound.”

⁴⁷ 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*.

the lost memories of the illnesses’ acute phase, the pain of certain procedures, the insistence upon isolation leading to grievous family ruptures

For midcentury psychoanalysts and rehabilitation physicians, 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.” Many polio survivors were “encouraged to forget their polio and put the past behind them.” Sheer and Luborsky. Wilson notes the following: Drs. Howard Rusk and Henry Kessler and Dr. Harold Visotsky

⁴⁸ Still this Johnson quote.

⁴⁹ 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/97808881634679>). 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.