The Marathon And On: Disability, Endurance, Aspiration

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The Marathon And On: Disability, Endurance, Aspiration

Abstract
This dissertation explores the ways ableism maintains itself in the latter 20th century U.S. through public dramas of the body staged as rituals of endurance that employ the marathon suffix, the -thon. The project focuses on some of the most legible, popular, and innovative -thons of the past several decades – the telethon, walkathon, danceathon, and hackathon – and uses archival and interview methods to trace the interlocking political agencies that make the -thon a potent cultural nexus. We offer that -thon rituals mediate notions of charity, independence, and pity not simply through speech and representation but through the management of the collective and conspicuously effortful body. In the end, we propose a way of thinking about the breath as an analytic, connecting the valences of the word "aspiration" so that we might imagine other, just aspirations.

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THE MARATHON AND ON: DISABILITY, ENDURANCE, ASPIRATION

Kevin Gotkin

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Communication

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For my mother, Colleen Kramer,

who has shown me the loving possibilities of endurance.
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THE MARATHON AND ON: DISABILITY, ENDURANCE, ASPIRATION

Kevin Gotkin
Carolyn Marvin

This dissertation explores the ways ableism maintains itself in the latter 20th century U.S. through public dramas of the body staged as rituals of endurance that employ the marathon suffix, the -thon. The project focuses on some of the most legible, popular, and innovative -thons of the past several decades – the telethon, walkathon, danceathon, and hackathon – and uses archival and interview methods to trace the interlocking political agencies that make the -thon a potent cultural nexus. We offer that -thon rituals mediate notions of charity, independence, and pity not simply through speech and representation but through the management of the collective and conspicuously effortful body. In the end, we propose a way of thinking about the breath as an analytic, connecting the valences of the word “aspiration” so that we might imagine other, just aspirations.
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CHAPTER 1: THE KIND OF PROBLEM A MARATHON IS

On August 6th, 1970, the Chicago Tribune reported on a six-day long basketball game on the North Shore of the city. The game was organized by a group of twelve teenage boys who called themselves the “Executive Committee for Abolishment of Summer Boredom.” Four three-person teams rotated every two hours for a total of 108 consecutive hours. “The main reason we are doing this,” said one of the organizers, “is to keep the kids [ourselves] ‘off the street.’”

The event was small. It played as an endearing story about teenagers making the most of the dog days of summer. But it fits into a mosaic of similar events that seemed to blossom around 1970. These kids may have been audience members of the annual Jerry Lewis Telethons, some of the most watched marathons in the latter half of the century. A year before this basketball game, Sydney Pollack was nominated for an Academy Award for his direction of They Shoot Horses, Don’t They?, a film that adapted Horace McCoy’s 1935 novel about a grueling dance marathon. The March of Dimes’ WalkAmerica launched in 1970, becoming the first major walk-a-thon in the U.S. Pennsylvania State University would launch an iconic dance marathon to raise money for childhood cancers in 1973. And over the course of the 1970s, participation in actual running marathons would soar.

In 1970, marathons were off to the races.

When most people hear the word marathon, they think of the long-distance running event that requires participants to traverse 26.2 miles. So what is being

referenced in the many marathons that don’t involve running, events that graft the marathon’s suffix onto other kinds of activities?

In the summer of 2015, a hot-tub-a-thon featured members of an Indiana fraternity collectively soaking in a hot tub for eight hours³, a see-saw-a-thon featured an Illinois high school student council taking turns on the playground ride for twenty-four hours⁴, and a shuck-a-thon at a San Diego restaurant featured seven chefs shucking more than 5,600 oysters over seven hours.⁵ These events occurred among an array of pet adopt-a-thons, bike-a-thons, bowl-a-thons, haircut-a-thons, walk-a-thons, and dance-a-thons that have taken place each week in the United States for decades. My dissertation focuses on the marathon’s suffix, tracks the places it travels, asks what this curious formation tells us about the culture from which it emerges, and then details the system of values it encodes in this variant but durable form.

In this chapter I set the parameters for the study by introducing the analytic framework I will use to understand *thons⁶ as cultural formations. I review the literature that helps us begin to understand what *thons mean. I review some data on contemporary *thons that helps us glimpse the portrait of endurance under investigation. And I propose my study as a novel approach to the problem, detailing key cases I will explore in the chapters that follow.

⁶ When I refer to “*thons,” I am employing the Boolean operator, an asterisk, that returns search results of all possible combinations of words ending in “thon.” I borrow this notation from the context of information retrieval, where it has a technical significance. Here, I use *thons to mean the full set of possible portmanteaux that have been and continue to be constantly configured. When I refer to the “-thon,” I mean the suffix itself or particular uses of the suffix.
Keyword: Marathon

We might be inclined to trace the etymology of the word “marathon” to get to the (linguistic) roots of the suffix this project traces. The word “marathon” derives from the ancient Greek word for fennel, in keeping with one version of the primordial marathon myth: In 490, Greeks claimed a prodigiously unlikely victory over the Persians invading the beaches of Marathon, after which a messenger ran approximately 40 kilometers to Athens to deliver the news, then promptly collapsed dead at the feet of the assembly. “Marathon” as a race refers to “Marathon” as a place, which was named for “marathon” as the word for fennel that covered (and still covers) the beaches in Southern Greece.

The marathon as we know it today was delivered by the birth of the modern Olympic Games in the late 19th century. It was officially introduced in the 1896 Olympic Games, inspired by excavations of Olympia and of a piece with the reverence of classical Greece that was au courant among the upper-class sport administrators of the day. A classical philologist named Michel Bréal proposed the marathon footrace to the chief organizer of the first modern Olympic Games, Pierre de Coubertin, during the preliminary organizational meetings for the Games in 1894. In the U.S. at this time, long-distance footraces were becoming increasingly common in the Northeast. Upper-class amateur sporting clubs were largely organized around ethnicity, drawing from spectacular competitions between native, colonial, and immigrant ethnic communities in the mid-19th century. “The excitement derived,” writes sport historian Melvin Adelman

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about an 1844 race in Hoboken, New Jersey that drew a crowd of 30,000, “from the fact that the white man beat the red man and the American defeated the Englishman.”

But it wasn’t until the 1960s and 1970s, according to marathon historian Pamela Cooper, that the marathon “became integrated with a number of popular beliefs about Americanism.” These include what historian Michael Goldstein calls the 20th century’s “health movement” that equated physical and national vigor and 1950s post-war nostalgia for small-town community that saw long-distance running as embodying “the pastoral idea of a simple life in harmony with nature.” Pamela Cooper traces the ways that major city marathons, like New York and Boston’s races, contributed to what she calls the “gentrification” of the American marathon in this period that attracted more middle- and upper-class suburban participants, grew the sports equipment and shoe industry for runners, and allowed top-level athletes to earn larger appearance fees. She documents, for example, the “visible hand” of Fred Lebow on the marketing and popularization of the marathon in New York City, which helped inspire the oft-cited “running boom” of the 1970s. The New York City Marathon in 1970 featured 127 starters, 55 finishers, and only 40 finishers in under 4 hours. By 1981, 4,000 finishers would complete the race in over 4 hours. The number of entrants overall increased roughly 10,000%.

There is, of course, much more to be said of the history of the marathon itself: its standardization, corporatization, and attachments to local, regional, and national

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11 Ibid., 122.
13 Cooper, *The American Marathon*, 123.
14 Cooper, *The American Marathon*, 141.
ideologies of health with inflections that varied from year to year. What scholars have not examined is the way that the marathon is grafted onto *non-running* events – and what this diffusion of the form might tell us about the culture from which it emerges.

The “–thon” is difficult to conceptualize as a single unit because although the suffix remains constant across events, particular designs and goals can vary greatly. In order to organize my analytic approach to this cluttered field of events, I have identified key features of the –thon that will help me explain how it endures and coheres over time. These same features, as I will explain in the larger work, illustrate the convergence of deep-rooted aspects of American culture.

**Collective physical activity.** I see a primary characteristic of *thons in the way they require physical activity. The role of the body in formal collective behavior is important in theoretical terms that will be explored later. For now we can note that a requirement of physical activity is particularly helpful in my project because it usefully excludes the many uses of the –thon suffix where the role of participating bodies is not a meaningful formal feature. Wikipedia edit-a-thons, for example, are increasingly popular events on college campuses across the U.S., but their goal is to collect knowledge (from subjects whose physical activity is not primarily important). Similarly, marketing events like Toyota’s annual “Toyota-thon” sales campaign are only tenuously associated with the key enactments of meaning under consideration here. While I note these instances with interest, my project traces the use of the body from the marathon into other kinds of physical activities and thus posits that the body is a central part of the symbolic circuit I aim to sketch.
**Temporal persistence.** *Thons create a unique form of temporality by asking participants to use their bodies over a long period of time. A *thon that lasts only a few hours – an ASCPA adopt-a-thon that happens for a few hours on a weekend, say – fails to manage time in the way that is characteristic to this unique form. Asking participants to walk or dance or give haircuts for a period of time that would otherwise be bizarre to perform alone or under different circumstances is part of how *thons attempt to produce the feeling that the event is unique, sealed off from regular time.

**Performance of conspicuous endurance.** *Thons distinguish themselves from other kinds of activities in their requirement that participants perform endurance. Related to the management of temporality, conspicuous endurance describes the way participants are encouraged to *perform* their experience of time and their use of the body. This means that many *thons feature bodies that are out of breath, sweating, staying awake into the night, or otherwise demonstrating or simulating sacrifice with other participants. In many cases, *thons are designed as competitions such that participants standardize and therefore compare their effortful endurance.

**Moral enactment.** The last defining feature of *thons is the way they transform physical tests of stamina into moral ones. The three previous characteristics of the ritual form are insufficient to draw participants into the activity; *thons need a cause. Often, this is couched in terms of civic participation. *Thons, I note, help to counterbalance an American ethos of individualism that would threaten the public weal without intermittent collective reaffirmation of commitment to communal well-being. This is one reason why many *thons are often directly related to fundraising, since American charity has developed in the private sector (whereas these roles are often filled by the welfare state
outside the U.S., one reason why Europeans are often unfamiliar with the *thon form). *Thons do not exist without a larger moral narrative that their physical activities help them achieve.

All of these characteristics are related. For example, a competitive element of *thons is tied to their moral enactment, even when all participants imagine themselves working as a team to “beat” a social ill, like cancer or leukemia or human trafficking. The altruistic formulation seen in many *thons (relaying for life, walking for the cure, biking for a cause) is one way we glimpse the above criteria working together.

Endurance is an important heuristic for the research throughout this project, informing the methodological approaches we take and organizing much of the evidence and substantive findings about how -thons attempt to achieve their work. The first definition of the word in the Oxford English Dictionary is “the fact of enduring (pain, hardship, annoyance).” But establishing “facts” of collective behavior is tricky business given the variance of structural and experiential characteristics in -thon events. One hopes for a measuring stick that might sort instances of endurance into various categories of “fact.” But this would cut the Gordian knot.

Even if we could, say, measure the heartrates of -thon participants at events across time and space, we would find a rather tenuous hold on the most important and transcendent aspects of what -thons are about. Attempts to measure the “facts” of endurance ignore the extent to which endurance is in fact a performative category, something communicated, evaluated, and achieved according to malleable and relational benchmarks. When endurance is assigned the status of “fact,” we can note the ways that this is an achievement of performance.
How do we know what endurance looks like? We might find it in the sweat-soaked shirts of danceathon dancers or the blisters of walkathon walkers. But enduring subjects often report their performances, relaying certain embodied experiences in language or style. Bloodshot eyes might not alone be understood as related to sleep deprivation until a participant mentions it, with an accompanying yawn. Some evidence of endurance, especially the report of pain, in fact does not have legible embodied markers. Is wincing a fact of endurance? Or can we open our analytic aperture wider to understand endurance as a communicative feat?

As will be explored in the literature review below, I treat the *thon as a ritual. In particular, I follow in the legacy of anthropologist Roy Rappaport who has argued that the body figures as the non-falsifiable element in meaningful human action. Indeed, Rappaport is well-cited as the most thoroughgoing of what are referred to as the “neo-Durkheimians” in part for his insistence that acts, in addition to utterances, form the communicative fabric of meaningful action. Rappaport’s work helps us understand that endurance, as a key concept in -thon analysis, resides in the embodied, linguistic, and social semantic communicative acts.

Rappaport indicates that a central “enactment of meaning” is not what rituals say about the state of a performer, but what they do. Rappaport argues that acceptance is intrinsic to liturgical performance and distinguishes it from belief. Belief suggests mental activities of ritual participants, “an inward state, knowable subjectively if at all.” In contrast, he writes, acceptance “is not a private state, but a public act, visible both to

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16 Ibid., 120.
witnesses and to performers themselves.” Describing the conditions under which an activity produces the “accepting self,” Rappaport writes, “It is the visible, present, living substance – bone, blood, gut and muscle – that is being ‘put on the line,’ that is ‘standing up (or kneeling down) to be counted,’ that is ‘putting its money where its mouth is,’ that constitutes the accepting agent.”\textsuperscript{17} Thus the physical body is a key conduit to the symbolic registers also involved in formalized collective behavior.

Thus we can understand endurance as a performance category that can be witnessed as -thon participants communicate their persistence to others. Following Rappaport’s focus on the non-falsifiability of the body in liturgical action, we can see how embodied markers of endurance produce more convincing performances than self-reporting alone. When we look for evidence of endurance throughout this project, then, we are looking for an array of bodily and communicative evidence with varying degrees of legibility, cogence, and coherence. And as we will discuss in the end of this chapter and in the conclusion, we take breathing as a uniquely salient and useful form of endurance to understand how -thons embed into American culture.

This Rappaportian theoretical orientation allows me to see the ways in which *thons enlist the body as the medium through which to enact American values about, among other things, health, fellow-feeling, and autonomy. By limiting the *thon under investigation to those that exhibit the four criteria listed above, I make my data sample more manageable. But this is not to say that uses of the –thon suffix in events that do not meet these criteria are somehow erroneous. I note these references as well, since they might offer me a window into the discursive formation of the *thon that exists in addition

\textsuperscript{17} Ibid., 146.
to its ritual formation (e.g., the pleasure of producing a portmanteau or the widespread recognition of the *thon form).

Another way I manage the size of an otherwise sprawling subject is by focusing on *thons as they have emerged in the United States. This is pragmatic, but not merely so. I begin from the assumption that *thons encode meaning that helps their participants grapple with intangible social abstractions. Rituals, Rappaport writes, “translate such important but incorporeal, complex and non-metrical aspects of social life as prestige, worthiness, honor, shame and influence into terms that are not only simple and metrical but also concrete.”\textsuperscript{18} This pedagogical element, we might call it, is specific to the communities that use *thons to condense and make operable social abstractions otherwise unavailable for direct and meaningful engagement.

Indeed much of this project aims to explain how. A great deal of literature in what can be called “body theory” seeks to understand what sociologist Norbert Elias would call Western societies’ “civilizing processes”: the ways in which etiquette and mores sought to domesticate bodily processes, from elimination to perspiration to sex.\textsuperscript{19} In Michel Foucault’s famous concept of the modern disciplinary society, authorities find success in the exercise of power not by brute force but by the indirect and invisible ways individuals internalize mechanisms of the self-control.\textsuperscript{20} This process reaches a fever pitch in its focus on the body in the U.S. when, as sociologist Bryan Turner argues, major

\begin{footnotes}{
\footnote{\textit{Ibid.}, 85.}
\footnote{Norbert Elias, \textit{The Civilizing Process} (New York: Pantheon Books, 1982).}
}
political and personal problems were “problematized in the body and expressed through it,” creating what he calls a “somatic society.”

This fixation on the human body takes on specific features within American culture during the latter 20th century, including the emergence and booming business of weight loss and fitness programs, consumer culture and commercial marketing focused on the moral value of keeping fit, and the attendant swell of mass media content preoccupied with shape and appearance as function of one’s personal identity. These tendencies combine with deeper currents of volunteerism that some historians of philanthropy have argued makes American political-philosophical commitments unique and anti-statist when compared to European welfare bureaucracies. Entrenched myths about individualism and work ethic that can be recognized as hallmark features of the imagination of American culture crop up in the formalized management of the body in the late 20th century.

Central to my project is illustrating how *thons formulate of a powerful ideal of ability that relies on disability as an abject corroborating converse to collective desires for normalcy. A disability perspective does important analytic work to unpack how *thons operate. After American Frank Shorter won the marathon at the 1972 Summer Olympics in Munich, he lamented being “disillusioned” by the “political influence” at the Games, referring to the horrific “Munich massacre” of Israeli athletes by the Palestinian Black September Organization. This dissertation considers how the marathon itself can be

understood to be “political,” albeit in far subtler and more diffused ways. In the chapters that follow, a disability perspective is key to unearthing the ways that marathons of all kinds propagate invisible and often uncontested ideals of ability, in turn influencing various social and cultural arenas.

The field of disability studies has extensively catalogued the various ways medical knowledge unduly determines the way disabled people are treated. Seen in this light, *thons are not simply about stamina, but about a circuit of values that shore up ability as a moral category imagined to be in danger of reverting into disease or disability. The *thon’s performance of endurance, then, cannot be thought apart from disability, even though ableist logics of progress often succeed at making able-bodiedness seem natural and therefore at a remove from disability. At the heart of my project is an insistence that disability crops up as a supremely useful category to ensure the coherence of the *thon’s moral center.

I follow in the legacy of “critical” disability studies that takes disability as a pervasive analytic, an agenda that resists efforts to minoritize disability as an identity category and instead uses it as a perspective to understand how many social and cultural domains benefit from keeping disability as a resolutely pathetic condition. This tradition, I’ve argued elsewhere,\(^{25}\) dates in part to French philosopher Georges Canguilhem’s midcentury work on the relationship between the normal and the pathological. This pair is quantitatively inverted, an important point that Canguilhem shows allowed modern medicine to determine its founding optimism in the capacity to return the pathological to

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its normal state.²⁶ Canguilhem sketched the ways in which this relationship was twinned in social and political order-making (e.g., in the way notions of the “norm” and the “average” became dominant ways to think about human populations) largely owing to the same theorists who helped establish it as dogma in medical philosophy.

My project continues this legacy by divining a concern for dis/ability in the *thon form even beyond the most readily recognizable ways. My research on the *thon notes how the form often constructs a form of medical progress (“the cure”) as the cause to which its physical tests help contribute (in funds or in “awareness”). *Thons often fixate and stabilize a notion of the medical model of disability by valorizing what biomedical innovation might do to redeem the sick and disabled body.²⁷ Throughout my project, I use this kind of disability perspective to unspool the skein of American values that tangles around dis/ability.

It may thus already start to make sense what will be born out in the empirical evidence of the following chapters: among the terrain of *thons in late 20th century American culture, there is a demonstrable proximity to disability. Many *thons – the most innovative and popular telethons and the majority of dance-athons and walk-athons reported in newspapers in the 1970s, for example – are organized with explicit reference to disability, most often as a form of fundraising for disability charities.

This delivers us to an important analytic question. In general, I will demonstrate how *thons are important for the way Americans think of themselves as a group. But this

²⁷ This insistence on the cure is not always bad. And strong critiques of the medical model within disability studies are quickly falling out of fashion in the field because they jettison the real, material consequences medical advances often make for disabled people. It is when medical progress is imagined as hermetically sealed off from the publics it serves, advancing according to some celestial idea of “progress” that critical disability studies makes its most important case.
leaves open a question that has rarely been answered with satisfaction: what kind of social order does the *thon produce? And how can we specify when these effects succeed and when they fail? Establishing the measures for understanding success and failure is a useful objective as part of our examination of the *thon form. Thus we might typologize the common stated functions (gathered from interview subjects and newspaper accounts) according to the forms of evaluation we can adopt and the potential results.

Table 1.1: *Thon Function & Means of Evaluation

<table>
<thead>
<tr>
<th>*Thon function</th>
<th>Means of evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brings the community together</td>
<td>Actors’ terms, bodily presence (amount of attendees, return attendance)</td>
</tr>
<tr>
<td>Helps disabled people</td>
<td>Following charity funds, evidence of stigma</td>
</tr>
</tbody>
</table>

It is important to note that potential success or failure given these means of evaluation are not mutually exclusive. For example, what disabled people may see as pity attribution in a *thon event may, for nondisabled participants, be understood as a *thon’s success in raising “awareness” about a disability. Later in the project we’ll explore how disability stigma is often a requisite feature of *thons that participants describe as successful, though disability activists routinely refuse stigma as an organizing strategy.

28 “Social order” is a freighted term in studies of ritual, often deployed as already functionalist. Here, we take “social order” as that which is normative within a community. That is, social order is mirrored in a community’s designation of what is a standard or norm. In this mirror, we do not assume that rituals effectively manage norms nor do we assume that normativity itself is a coherent or uncontested process.

29 One important way to understand an organization’s stated impact is to analyze their spending, which is often reported in the public domain on 990 forms. Though measuring a charity’s “impact” is a fraught field that has its own network of regulators and analysts (notably GuideStar USA, Inc. that databases millions of American nonprofits), it is nonetheless important to know whether most of a charity’s funds are spent on, for example, biomedical research support or on wheelchair or ventilator costs for beneficiary families.
I match this theoretical orientation to the *thon with a considered methodological design. In addition to surveying the *thon as a contemporary event form across the United States, I have chosen cases that I believe give me access to some of the most important developments about the ritual over the latter half of the twentieth century.

**What a Marathon Is**

Though there are fragments of scholarship about some elements of the cases I put together in this project that I will cite as necessary throughout, there is, simply put, no literature on the mosaic of physical cultural activity I identify as the *thon form in the late 20th century. And yet the linkages between the various kinds of –thons – the telethon, dance-athon, walk-athon, and hack-athon – become legible within a larger web of citations. In this section I survey the terrain of scholarship available for making sense of *thons and arrive at a theoretical frame tailored to elucidate the most important dynamics of the *thon form so that we can usefully assign it a status (that of ritual), which we will use to set the stage for the analytical advancements of the following chapters.

While we have no existing topical treatment of the *thon, our intellectual legacy in fact begins with the study of a particular media marathon. In *Mass Persuasion*, sociologist and communication scholar Robert Merton sought to understand the extremely popular and successful war bond drive hosted by Kate Smith during radio “marathons” in September 1943. Smith made 65 short appeals over 18 hours to about 23 million listeners, which resulted in about $31 million dollars (or about $4.3 billion today) in war bond purchases in a single day.³⁰ Merton’s study, a combination of content analysis and interview methods, sought to explain how Smith’s “public image” and

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patriotic appeals enabled such an astounding media effect. Attendant to his work with Paul Lazarsfeld in this period that announced the paradigm known as “limited effects,” Merton’s study demonstrated the essential contingencies of persuasive media that reversed decades-long commitments among early media theorists about the supposedly uniform and powerful effects of media.

Reflecting on the utility of returning to Merton’s text today, communication scholar Peter Simonson places Merton’s original study in a lineage that includes Kurt and Gladys Lang’s study of live broadcast events in the 1950s, Daniel Dayan and Elihu Katz’s typology of “media events,” Barbie Zelizer’s study of media’s role in the collective memory of the Kennedy assassination, and Nick Couldry’s 2003 appraisal of the nexus of ritual and media studies.31 As the breadth of these citations indicate, Merton initiated an entire topical and methodological sphere within media studies.

The event, for Merton, is a rich unit of cultural activity.32 For Kurt Lang and Gladys Engel Lang who would continue Merton’s work to help define the field of communication studies, General Douglas MacArthur’s visit to Chicago following his

32 It should be noted, though, that there is a separate but rich intellectual tradition that treats the “event” very differently – even at odds with this approach in communication studies. 20th century philosophical writing focuses less on processes of signification in formal collective behavior than on the capacity for emergent relations to disrupt the reality as the conventions of perception. Alain Badiou defines the event as that which punctures the ideological forces that cover over what is the “void” of “inconsistent multiplicities” that make up reality. The state’s capacity to “count-as-one” in a given situation – that is, to retroactively designate a one-ness among ongoing multiplicities – determines collective agreements of happening, which is one noted utility of Badiou’s well-cited “set theory.” On the level of ideology, the count-as-one function helps keep the threat of multiplicity at bay by covering over ontological multiplicity that threatens what is perceived as order. The “event,” for Badiou and others including Gilles Deleuze and Slavoj Žižek, then becomes those aspects of the excluded multiplicities which rupture dominant ideology and designate social locations outside that which is made legible through the count-for-one function, which is actually makes the event that which interrupts what we are designating here as the capacity for rituals like *thons to produce collective agreement about what not to disagree about. Alain Badiou, Being and Event, trans. Oliver Feltham (New York: Continuum [1988] 2005); Gilles Deleuze, The Fold: Leibniz and the Baroque (Minneapolis: University of Minnesota Press, 1993); Slavoj Žižek, Event: A Philosophical Journey Through a Concept (Brooklyn: Melville House Publishing, 2014).
abrupt dismissal by President Truman, called MacArthur Day, presented a unique research opportunity to study the effects of television’s live broadcasting of the “public event.” They cast early doubt on claims about television’s capacity to bring “the truth directly into the home” and named a “technological bias” that produced selected and stylized frames of the event that differed significantly from the experience of physical co-presence at the affair.

As part of their focus on the role of television, they held the “public event” as a kind of constant, an occasion for the broadcast but not itself an object of inquiry. But Daniel Dayan and Elihu Katz pick up where Lang and Lang leave off in their eponymous monograph on “media events” that seeks to paint a fuller portrait of how live events get broadcast into history. They define media events as preplanned, non-routine live transmission of public events. Drawing on Weber’s tripartite typology of authority, they identify three kinds of “scripts” in media events: contests (such as the Olympics), conquests (such as the first step on the moon), and coronations (such as British royal ceremonies, the topic that inspired much of the literature Dayan and Katz drew from). In defining the rhetorics involved in events that seem to “hang a halo over the television set,” Dayan and Katz helped lay out a broader portrait of the event as it was being incorporated into new and increasingly pervasive potentials of electronic media.

35 Specifically Shils and Young.
36 When media events are not preplanned, we sometimes refer to them as “disaster marathons,” as Tamar Liebes has analyzed as an extension of Dayan and Katz’s original examination. Tamar Liebes, “Television’s Disaster Marathons: A Danger to Democratic Processes?” in Media, Ritual, and Identity, eds. Tamar Liebes and James Curran, 71-86 (New York: Routledge, 1998) and Menahem Blondheim and Tamar Liebes, “From Disaster Marathon to Media Event: Live Television’s Performance on September 11 2001 and 2002,” Prometheus 29, no. 3 (2002).
37 Dayan and Katz, Media Events, 1.
Though it seems like these citations cohere around the notion of an “event,” they in fact deal in a variety of related concepts that we want to use to understand the *thon. So the question remains: What is a *thon? A ritual? An event? A performance? A gathering?

As noted above, an essential theoretical move for this project is the capacity to read collective behavior for what it reveals about cultural value systems. Since Émile Durkheim’s 1912 classic *Elementary Forms of Religious Life* provocatively proposed that “god and society are one of the same,”38 generations of social scientists have turned to ritual to explain the transcendent features of everyday life that attempt to produce what we perceive as order, control, and continuity in human relations.

In general, theorists tend to define ritual as collective, patterned, rule-governed activities, malleable yet invariant, whose meanings and motivations transcend individual participants, and whose symbolic categories correspond to social categories in order to foster order (without necessarily succeeding).39 Rituals direct the attention of a collective to certain values, often by relying on distinctions that valorize certain symbols and symbolic actions (the sacred) while rebuking others (the profane)40 such that unequal social actors can coordinate or resist the scripts of collective integration.

This framework has been debated, extended, and nuanced throughout the 20th century, perhaps most notably in what is often called the “linguistic turn” in anthropology.

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40 Durkheim, *Elementary Forms of Religious Life*.
typically dated to the 1970s. In his 1972 classic “Deep Play: Notes on the Balinese Cockfight,” Clifford Geertz proposes the important neo-Durkheimian principle that cultural activity is organized less through “social mechanics” than “social semantics.”

“[C]ultural forms can be treated as texts,” he writes, “as imaginative works built out of social materials.” This literary approach was meant to correct the gaps in utilitarian or functionalist approaches to culture, namely Jeremy Bentham’s notion of “deep play,” that would, as it were, miss the forest for the trees by focusing too narrowly on the role of money and exchange in the kind of cultural activity a cockfight is. Instead, Geertz argues, the disarranging of semantic contexts in order to ascribe them onto unconventional contexts – the cockfight as a condensation of the status among men – more fully captures what he sees as the meaning of culture. “[S]ubjectivity does not properly exist until it is thus organized,” he writes. And thus “art forms generate and regenerate the very subjectivity they pretend only to display.”

This re/generation of subjectivities is a key insight from mid- to late-century cultural anthropology because it explains the draw, the coherence, and the pedagogical dimensions of cultural events: we learn what values course around us when they take form in meaningful events. And as Geertz identified in 1972, cultural activity

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42 Ibid., 27.
43 Ibid., 28.
44 This point is tangential but related to another debate in the study of ritual, which is whether “ritual” as it was theorized by its early proponents, even exists at all in stratified, late capitalist societies since accelerated advancement of technologies and the displacement of communal ties (Gemeinschaft) with alienating relations of industrialization (Gesellschaft) has weakened the transformative potential of ritual. Nick Couldry makes this problem the direct focus of his “critical approach” to media rituals by explaining how rituals rely on a “myth of the mediated center” without guaranteeing the ontological existence or success of this center. Jeffrey Alexander goes so far as to claim that what we have today are not true rituals, but only activities that are “ritual-like.” Nick Couldry, Media Rituals: A Critical Approach (New York: Routledge, 2003) and Jeffrey Alexander, “Cultural Pragmatics: Social Performance Between Ritual and Strategy,” Sociological Theory 22, no. 4 (2004): 527-573.
“pretends” to merely display subjectivities and may even actively refuse the acknowledgment that it in fact produces subjectivity. In other words, cultural forms such as cockfights or marathons are often discussed as only channels for the flow of meaning when in fact they craft, shape, and produce meaning. Thus the analyst, to following Geertz’s suggestions, must take up culture as a network of texts that can be “read” for underlying social semantics.

This move towards the literary interpretation of culture could also be located across the humanities and critical social sciences over the 20th century: in Johan Huizinga’s insistence on the “serious” advantages of identifying the “play element” in culture, in Herbert Blumer’s school of symbolic interactionism that centers meaning produced by signification between individuals and society, in Goffman’s interest in the formalizations of the “encounter” or “focused gathering.” In these examples and more, social activities themselves become media for the analyst to interpret.

But if culture is a web of signification, does the living, breathing body disappear?

This is a bone of contention that deserves fuller examination. For example, in focusing on television’s transformation of events and not on the phenomena of the events themselves that precede their televisuality (even if they may be significantly changed by the process of mediation), Dayan and Katz leave the role of the body in media events relatively undertheorized. Especially in their analysis of the contest and conquest event scripts, the performative able body represents the terra firma on top of which the event does its work. While some emerging literature has attempted to coin some terms of art we could use to begin to unpack the body in the event – such as “physical culture” and its
nationalistic inflections at the Olympics\(^45\) – this scholarship doesn’t treat the event as its own unique set of relations we seek in order to situate the *thon form.

Perhaps the most comprehensive way of linking theories of ritual, communication, and the body comes from Carolyn Marvin and David Ingle’s *Blood Sacrifice and the Nation*, which examines how the American flag’s totemic reference to sacrificial American soldiers’ dead bodies offers the flag its symbolic centrality in the communicative apparatus of American patriotism.\(^46\) The study’s attempt to analyze the flag’s totemic status as a communicative vector alongside but independent of other forms of language is one of its major interventions in the way, as I am outlining here, theories of media ritual often sideline the important communicative work of the body. In addition, Marvin’s earlier work on the relations between the body and text – the former being trained to disappear in service of a sophisticated textual order\(^47\) – informs a generalized approach to understanding the cases at play here whereby the body is supposedly redeemed but also disciplined by forms of textualization that incorporate what disability scholar Tobin Siebers has called the “ideology of ability.”\(^48\)

As mentioned earlier, Roy Rappaport’s formation of *acts* in addition to the utterances involved in ritual and the key conduit of the *body* as a vehicle for rituals’ “enactment of meaning” help us focus on the primordial bodily co-presence involved in *thons of many kinds that then may be mediated in various forms and transformed as each enrolls audiences and participants in unique ways. But key to Rappaport’s insight is

that what bodies do during collective behavior bears important markers of the meaning contained within cultural activity.

Marvin’s work on the embodied communication at work in powerful rituals, which continues the Rappaportian tradition, helps us understand what we can see as *thons’ unique management of the body, which will be key throughout the project’s theoretical treatment of the following cases as rituals. Direct sacrifice of life can be seen as the most transformative form of ritual, as in the case of war. But *thons require a far more oblique, symbolic, and all together harder-to-hold kind of sacrifice, one that indicates the experiential qualia of participation demands nuance in designations of ritual status.

It is this slipperiness, obliqueness, and symbolic management of the body that makes *thons powerful mechanisms of culture. The literature I have surveyed here can help us see how *thons operate at the kind of mundane background knowledge about the kind of bodies imagined as strong, civic figures and those deemed in need of repair, help, or charity.

“Health” Communication

The field of disability studies offers some excellent tools for understanding how collective desires for normalcy mark and distrust certain bodies as deviant. Early disability scholarship in the U.S. is often dated to the 1970s when people whose subjectivities had been determined by doctors, who were institutionalized, experimented

on, and too often exterminated “came out,” as disability scholar Simi Linton puts it.\(^{50}\) Emerging alongside disability activism that benefitted from the gains made in other identity politics fields at the time, this early research sought to overturn widespread ableism that left disability as a monolithically inferior social category. Since the early days of disability scholarship, the field has developed into what early disability scholar Rosemarie Garland-Thomson called in a 2013 review essay “a field emerged.”\(^{51}\)

Disability scholars have insisted that disability is a universal category of relations, with deep-rooted contiguities with race, ethnicity, class, gender, and sexuality.

Disability’s temporal vicissitudes – that it bids entry in a heartbeat or, if we live long enough, over time – make it particularly useful in intersectional analyses. In addition to the vagaries of war, poverty, and disaster where we can well see how vulnerable populations are disabled,\(^{52}\) very few social categories of any kind are exempt from disabling experiences.

One important concept in this vein is what can be called, following Eve Sedgwick’s formulation in queer studies, a “universalizing model of difference.”\(^{53}\) Disability, in this line of thinking, is more than a minority that can lobby for legal-political rights by relying on a supposedly evident distinction between “normal” and “disabled” individuals. Disability instead is an experience that all individuals tend toward


with age, experience unpredictably, and actively ward against in mundane biopolitically-disciplined routines. A radical anti-assimilationist agenda that Robert McRuer inaugurated in his book *Crip Theory* takes this universalizing model to insist that what he calls “compulsory able-bodiedness” is a powerful script, with strong neoliberal inflections, that determines a centrifugal pull toward a performative able-bodied core, according to which certain lives are deemed worthier than others. Thus “disability” can be thought of apart from the human altogether; it is instead “the open mesh of possibilities,” as Sedgwick would say, always available to be thought otherwise for more accessible worlds.

The universalizing at the heart of disability studies has given the field much of its analytic power. “To speak at all pertinently of disabled people is,” as French theorist Henri-Jacques Stiker writes, “to disclose a society’s depths.” A consistent foregrounding of this universal model of difference is what some say distinguishes “critical” disability scholarship from the larger field. Critical approaches to disability seek not to locate and define disability, but to excavate the ways disability pervades its many contiguous social domains. As British disability scholar Dan Goodley writes, “Critical disability studies start with disability but never end with it.” Critical approaches seek instead to illustrate disability’s enduring and widespread manifestations. This tradition finds disability in, for example, the many iterations of American

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justifications of inequality, from the diagnoses assigned to slave bodies as proof of their incapacity to be full citizens to similar early 20th century logic that women, if given full access to suffrage, would become unhealthy mothers.\textsuperscript{58} Contemporary critical disability scholarship now finds and illuminates disability as a verb or assemblage or ideology – all active forms that exceed what “first wave” disability scholarship was attempting to set boundaries around.\textsuperscript{59}

All this suggests a certain irony in thinking of disability as a “minority” category. And yet an enduring paradox in disability studies is how rarely disability is taken up as a core analytic in social analysis, despite the evidence that it is all around us. “Disability is everywhere in history, once you begin looking for it,” writes historian Douglas Baynton, “but conspicuously absent in the histories we write.”\textsuperscript{60} While disability studies as a field has gained a certain amount of visibility and professionalization, a number of disability scholars point out that even in the academy, it is more useful to keep disability as an abject, pathetic type than build the ramp to invite it in the front door.\textsuperscript{61} As a result, disability seems both everywhere and nowhere.

Representation has been a core analytic in the birth and rise of disability studies. An important charge in the rise of the field has been to write people with disabilities back into the stories they have been left out of. Not only who gets written about, but who gets “seen” and “heard” – metaphors at the nexus of communication and the body that register


\textsuperscript{59} For a discussion of the “waves” of disability studies see Paul Longmore, Why I Burned My Book and Other Essays on Disability (Philadelphia, PA: Temple University Press, 2003), 53-87.

\textsuperscript{60} Baynton, “Disability and the Justification of Inequality in American History.”

the recognition of a meaningful life – have been crucial avenues of exploration for
disability studies. As a result, literary disability studies has produced some of the most
nuanced and productive theories for other parts of the field. These theories illuminate the
pervasive use of disability as a narrative tool in literature but not a valid lived condition
in itself (“narrative prosthesis”), the agency of people with visible disabilities when the
“normate” gaze sees their condition as the result of some tragic story (the “visual
rhetorics of disability”), and the “historical diffraction” of the discursive deployment of
disability as a constitutive component of the real.

These robust theories of representation in disability studies go hand-in-hand with
the high status of social constructionism in the field, which is widely regarded as
foundational in developing the “social model” of disability. Put simply, the social model
emphasizes that while certain bodies may be impaired by their unique features, disability
is not a natural category but one that is created by society’s refusal to, for example, build
the ramps necessary to allow those who use wheelchairs to access the built
environment. While generative and powerful in how it casts social relations as
malleable and contingent, this paradigm has recently been questioned for whether it can
account for the full complexity of disability. The social construction of disability suggest

62 Mitchell and Snyder, Narrative Prosthesis.
Photography,” in The New Disability History: American Perspectives, eds. Paul K. Longmore and Lauri
64 Stiker, A History of Disability.
65 British sociologist Mike Oliver is usually the person credited for diffusing the social model into academic
work. Oliver fashioned the social scientific model after activist work in Britain. In their “Fundamental
Principles of Disability,” the Union of the Physically Impaired Against Segregation writes in 1975: “In our
view, it is society which disables physically impaired people. Disability is something imposed on top of our
impairments, by the way we are unnecessarily isolated and excluded from full participation in society.”
Mike Oliver, Social Work With Disabled People (New York: Macmillan, 1983); Union of the Physically
Impaired Against Segregation, “Fundamental Principles,” Leeds University Centre for Disability Studies
a certain tautology whereby oppression is taken to be a key metric in defining disability, which then means that social constructionism, to borrow from Tom Shakespeare’s gloss on the conundrum, “assumes what it needs to prove: that disabled people are oppressed.”

Tobin Siebers offers a more trenchant critique of the social model, pointing out that although it was originally a crucial political strategy for reversing essentialized notions of the inferiority of disabled people, it has analytically divorced itself from the material dimensions of disability and thus risks ignoring the very real problems that disability brings to the fore. For all its flaws, the medical model at least took seriously the materiality of disability that a strict social constructionist view staunchly denies. Siebers’s call for a “new realism of the body” is meant to refocus our attempts to understand disability not on abstracted fictions of value systems, but instead on the real, physical dimensions of disability experiences. Disability scholars’ focus on representation has made it clear that the field is currently rent between representationalist and materialist ways of conceiving of the body, handed down by competition between formidable ways of seeing the world that the social and medical models offer.

For as much as these treatments seem to implicate core questions at the heart of communication studies, disability scholars have rarely taken up communication in earnest. Absent is a thorough and sustained account of what these two hulking terms mean to each other. The fields share a great deal, especially in their status as “fields,” not disciplines, that crib from established arenas while promising to overturn existing academic paradigms. Routinely in danger of losing their specificity all together by dint of

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67 Siebers, Disability Theory, 2008.
their success in signaling their own capaciousness, both “disability” and “media” need to be elucidated simultaneously. That both disability and media have their own “worlds” while contributing greatly to an enlarged sense of “the world” itself suggests there is much grist for the mill.\textsuperscript{68} Excavating the shared ground between these terms (and fields) is one of the primary goals of my study.

My tongue-in-cheek reference to disability-media studies as “health communication” in fact has an earnest motivation. What we usually mean by “health communication” is a subfield that descends from an effects tradition with the medical model lodged firmly at its core. But what “health” communicates is hardly contained in questions of media effects or the narrow set of questions that emerge from what public health organizations are willing to fund. Understanding how health communicates and is communicated signals a much wider landscape, including an alternative “health communication” that tries, as my study does, to bring disability to the fore in understanding how medicine and society interact.

Method

“Diverse and scattered, such is the state of our information.”\textsuperscript{69} This is how French theorist Henri-Jacques Stiker describes the sources available to glimpse the “mental universes” that govern the relationship between disability and society. In \textit{A History of Disability}, Stiker explains why historical evidence on the discourses of disability is so hard to hold: largely because attempts to integrate disabled people into society naturalize themselves and make it hard to directly query. For this reason, Stiker notes in an “interlude on method” that to map a constellation of the language that crops up around


\textsuperscript{69} Stiker, \textit{A History of Disability}, 20.
disability – and to remap as the constellation evolves – requires what he calls “historical anthropology.” Building on the work of Claude Lévi-Strauss, Stiker sees the objects of anthropological inquiry as signs, instances of utterances, and forms of discourse.

This leads Stiker to the singular work of history. To understand what “adaptation” or “rehabilitation” meant in various moments, as Stiker attempts, means writing “a” history of disability. This call to historicize, always historicize, means something unique for the study of disability, since how society talks about and manages impairment drives straight to the heart of that society’s order-making mechanisms (even when they fail) and thus the need to specify and contextualize any given instance of disability discourse is ever greater. What Stiker models in his work is a way of using discourse as an entrée into the whole system of “mentalities” about disability, a system that, once sketched, offers a formidable portrait of society itself.

But as we explored in the literature review above, speech and discourse alone do not give us full access to the complexity of marathons in American culture. As Roy Rappaport has said of ritual communication, there “is not simply an alternative way to express any manner of thing, but that certain meanings and effects can best, or even only, be expressed or achieved in ritual.”70 For method, this means analysis must incorporate the study of participants’ speech, the discourses that code this speech, as well as the collective physical activity and meaningful objects all involved in ritual proceedings.

My project takes up the -thon following Stiker, treating –thons as circumscribed by a web of values about ability. We could thus call my project “anthropological,” to follow Stiker. But it seems to me that it is necessary to be more precise about a method

70 Ibid., 30.
here, since “anthropological” or “ethnographic” has recently become such a cloying way to think about method in media studies that it’s nearly emptied of the specificity the adjective once offered. Saying a study is “anthropological” is often saying nothing more than that it seeks to incorporate many kinds and levels of evidence into the analysis, which is a methodological imperative too fundamental in my project to name as if it is a technique all its own.

A more specific way to think about my method derives from the legacy of French philosophy from which Stiker descends, including Michel Foucault but starting with Georges Canguilhem. Canguilhem, though less well-known among Anglophone audiences for his philosophy of biology and medicine, inspires much of my project’s theoretical orientation to the –thon (and, as I have argued elsewhere, also a theoretical core to the contemporary field of disability studies71). In Canguilhem’s dissertation, The Normal and the Pathological, he sets out to describe how the birth of modern medicine relied on faith in a key dichotomy between the normal and its opposite, the pathological. This pair is quantitatively inverted, an important point that Canguilhem shows allows medicine to find its founding optimism in the capacity to assuredly return the pathological to its normal state.72

To arrive at the kind of epistemological excavation this argument required, Canguilhem employed what he calls a “recursive method” (“méthode de récurrence”), a challenging but powerful orientation to language that attempts to dissolve crystallized

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concepts into the solutions from which they precipitated. This approach is antiteleological, attempting to disregard what we know as the outcomes of contemporary histories of medicine so that we can better understand how a concept came to be crystallized at all. Canguilhem’s “historical epistemology,” writes Arthur Goldhammer, offered a tenable alternative to historical projects that were tempted to see forms of knowledge as timeless and overly subject-centered, an alternative that lived on and was expanded by Michel Foucault and Gaston Bachelard, two of Canguilhem’s many mentees. In my project, I take inspiration this historical epistemology, approaching the –thon as a crystallization of American culture that needs to be dissolved back into its historical solution.

Paired with this recursive methodology is my concerted focus on documentation. A number of disability historians have flagged the many methodological challenges of finding disability in the archive, since doctors have typically controlled the reigns of how “patients” get represented by dint of the institutional heft physicians often held. Not just who gets to speak can be a complication for cultural historical work on disability, but also how disability is spoken about. One of the persistent challenges, as mentioned above, is in ferreting out disability discourses when the discursive apparatus that produces them is so deft at covering over the ideologies of ability that attempt to make disability disappear.

**What We Talk About When We Talk About –thons**

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These demands of documentation compel creative ways to access evidence in this project. The following chapters take particular -thons for analysis, each of which I argue are exemplary cases in the larger *thon mosaic. In those chapters, I detail my sample selection as it relates to a chapter’s periodization. It is helpful, however, to begin with a survey of contemporary *thons as a snapshot of the techniques and formations we will explore in greater depth later.

Though ritual communication is irreducible to its speech and texts alone, we can begin a preliminary sketch of American –thons by thinking about what tends to be said about marathons. In April and May 2015, I logged and mapped all new Google search terms returned on the –thon suffix. I did so by collecting results from daily Google Alerts reports. Google Alerts catalogs new results on a given search term from content that its robots crawl and index across the internet. Many Google users rely on the service to be kept informed about new developments online relating to a particular topic (e.g., being alerted when your name is used online).

Google Alerts is a convenient and simple solution to a unique problem of my study: How to collect instances of marathons that happen all around the country without being easily accessible in a single location. While Google Alerts cannot provide information about every marathon – there are, for example, many –thons that are not written about online and many more that are not publicly available to Googlebot, Google’s main crawler – it gives us a good sample of events to work with for this preliminary survey of marathons around the U.S.

Every day, I received a list of the Google Alerts results on the search term “*thon” (the Boolean operator to return all permutations of words that end with “thon”).
While the amount of results varied each day, typically new instances of the –thon suffix on Google’s searchable content ranged from 50-100. I then logged each of these results in two places: a database in DevonThink (the organizational software I use for data collection for this project) and Google Maps. In each database, I collected the following data categories: name of event (e.g., walk-a-thon, bike-a-thon, etc.), location, date of event, and the link of the Google-indexed URL.

I chose April and May of 2015 as my selection months for two reasons: 1) In most parts of the U.S., this is the time when warmer spring climates bring out the start of an annual cycle of public events that continue through the summer, and 2) The search results that are indexed in the Google Alerts data are often local newspaper announcements of upcoming events. Thus cataloging search term results in April and May collected not just events happening in those months, but also –thons that were planned for the rest of the summer. That said, the sample is nonetheless limited to two months in 2015 and thus it is important to keep in mind that the cross-sectional and temporally bounded sample constrains the kind of extrapolations we can make from the data.

There was only one criterion for exclusion from this –thon database: natively digital “-thons.” After beginning my data collection, I realized that each day I would receive approximately 3-5 results on a search term that related to the use of the –thon suffix solely for an online-only activity. For example, YouTube book bloggers and Reddit video game fans would often coordinate a distributed collective campaign (e.g., a read-a-thon or video game playing marathon) solely online. These instances of the suffix are markedly different from the other search results that referred to collective activity together in physical space. As will be explored below, not all of the marathons that
happen in physical space are meaningfully fashioned as marathons, but the online-only marathons deviate even further by lacking a sense of place, which also makes it impossible to map.

Fig. 1.1: This screenshot of the Google Maps data shows red markers, indicating where a –thon has been logged.

There were 760 *thon events during the sample period, with 221 different names of events. Appendix 1A shows the full list of events sorted from most common to least common.

Having established this cross-section of –thons, I turned to interview methods in order to get a better sense of how participants imagine their work in organizing marathons and what kinds of schemas they have developed for talking about their events.

I randomly sampled 50 events from my database of –thons in April and May of 2015, using the random number generator in Microsoft Excel with boundaries of the total number of entries (1-760). Because my focus is on the U.S., I excluded the few international events that were sampled in. I found the corresponding contact information
for each event’s principal organizer and made contact through email, requesting a brief interview by phone. A copy of the recruitment email can be found in Appendix 1B, as well as information about the random sample responses.

I requested interviews starting in May 2016, about a year after I had originally collected the Google Alerts data. I did this for two reasons: 1) I wanted a considerable amount of temporal distance from the original event, anticipating an interview bias toward speaking about their organizing work as successful in the immediate period following their –thon, and 2) Because many –thons are annual, I caught many participants in the organizing period before their next –thon and was thus able to question organizers about their year-to-year campaigns. Those who were not organizing annual events were in a position to offer candid responses about last year’s efforts and those who were continuing an annual event were able to speak to ongoing work.

25 –thon participants agreed to be interviewed and recorded.75 24 of the organizers I contacted did not return my email and 2 declined to be interviewed. The interviews were semi-structured, lasting between 10 and 20 minutes (the shortest lasting 5 minutes, 17 seconds and the longest lasting 28 minutes and 12 seconds). The interview protocol I used to structure my question progression can be found in Appendix 1D.

Since these interviews were designed to give me access to the breadth of –thons that occur across the U.S. each week, a survey of many small local events that can be paired with considerably deeper probes into the choice marathons that make up the rest of this project, I had a number of objectives in mind when standardizing my questions across interviews: 1) To understand the different logistical designs of the –thons, 2) To

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75 I interviewed two participants about the same event, a Drum-a-thon benefitting children with cardiac diseases, after the first interviewee referred me to the main participant.
understand how and why the events take place, 3) To understand why organizers use the –thon suffix in their event names (and if there was another event they were modeled theirs after), and 4) To understand how participants measure success of their organizing work. Each of my interviews progressed through questions designed to get at these objectives, in order, but I sometimes dwelled on one or another question in order to allow flexibility for participants to signal their own emphasis.

After reviewing each interview recording, I coded them for the various responses to questions that probed each of these analytic objectives. The results are helpful for gaining a closer look at what motivates the work behind the hundreds of marathon events that happen across the U.S. each week.

1. Variants of –Thons

Perhaps the most obvious point in reviewing these interview data is that there are many different ways that the –thon suffix gets used and there are many different logistical formats for the –thon. This means that not only are there many kinds of activities that come before the “-thon,” but that the events themselves have many different designs, temporalities, and objectives.

The first kind we can identify is what could be called the short-format –thon. These are events that last less than half of a day, usually only a few hours. A “Spin-a-thon” at a YMCA in Malden, MA referred to 3 back-to-back cycling classes taught by the same instructor, with an entry fee that raised a modest amount of money for the Y’s Healthy Living programs. A “ROCC-a-thon” in Indianapolis had a similar brevity. The name refers to both the acronym for the organization’s name, Reaching Out to Citizens
Affected by Crime, and the activity of rocking in rocking chairs that participants were invited to do – but the event lasted only from 10am-2pm.

Other organizers I interviewed told me of similar short formats: a “Jail-a-thon” in Bladen County, NC that runs for a Saturday afternoon, where local businesspeople are “locked up” until they make a donation or call friends who make a donation large enough to get them out; a public library “Read-a-thon” in Portage, MI with class visits for a morning; 2 “Walk-a-thons” (one in Jasper County, NC and the other in Tucson, AZ) involving people circling a track on a weekend morning; a “Trail-a-thon” on a Saturday morning in Sudbury, MA consisting of a guided tour of a public parks system; a Friday evening “Bowl-a-thon” in Chesterfield, MO as a fundraiser for an education organization; and a “Prayer-a-thon” in Panama City, FL in which church-goers prayed under various signs with the names of area schools on them for a total of 2 hours.

A similar event type is the full-day and multi-day format –thon. These events are distinguished from the short format by their temporal persistence, which introduces variation to the organizational structure. For example, a “Chalk-a-thon” in Quincy, IL involved participants at an arts festival coming and going from an area of concrete, drawing chalk images and filling the ground-canvas together. But other team-like activity was more structured: a “Paint-a-thon” in Omaha, NE involved groups of volunteers painting the houses of elderly and disabled citizens in one long day of painting. A distinction in full-day events can be made between relay –thons, like a “Banned Books Read-Aloud-a-thon” at a public library in San Diego where many readers took turns

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76 The “Jail-a-thon” in fact has a long and curious history, often being a regular feature of the local programming on MDA Telethons. MDA continues to hold “Lock Up” fundraisers, in interesting proximity to the discourses of imprisonment that circumscribe disabled people by pity-dealing organizations.
reading out books that have been censored, and events where participants experience the activity for the duration of the –thon, like a “Live-In-Your-Car-a-thon” hosted by a church in Santa Rosa, CA that involved participants living in their cars for 24 hours to simulate the plight of homelessness.

Other full-day format event organizers I interviewed included 2 “Fast-a-thons” (one in Chicago and one in Boston) designed to introduce non-Muslims to the core principles of fasting during Ramadan; a “Piano-a-thon” in Salt Lake City, UT that featured a rotating piano player for 88 hours (one hour for every key) to raise funds to purchase a new Steinway for a local arts center; and a “Shack-a-thon” at Virginia Tech that required teams to have at least one person in a team-built structure at all time for a week.

This format has particular analytic utility for the project writ large because it requires the performance of conspicuous endurance and puts this endurance on display more than the other formats outlined here. This helps demonstrate the key roles of the body in –thon rituals, discussed above in the literature review as an important intersection within the theoretical apparatus for the project, and also helps elucidate ritual dynamics that can be seen across other formats.

The third kind of event structure is the non-exclusive participation –thon. This kind of event will last much longer than a day or few days, but will not require the full and exclusive attention of its participants. The –thon can be said to function in the background of daily activity. For example, a “Chip-a-thon” in Marshall County, AL was the name given to a month-long campaign to get animal owners to visit a veterinarian’s office to have their pets tagged with a microchip to be located after a natural disaster.
Similarly, a summer-long “Read-a-thon” in New York City was designed to have students collect donations for school fundraising while continuing their reading skills outside the classroom. A public radio “Fun-a-thon” funding drive in East Orland, ME and a fundraising campaign for a San Francisco Bay conservancy group called “Bay-a-thon” took a similar format requiring only intermittent attention to a campaign that lasted a week.

The last and most uncommon event type in my data sample is the endurance –thon. This event structure is closest to a long-distance running event and requires unusual commitment to a single activity by a participant or participants for an extremely long period of time. In my sample, I interviewed two people involved in a “Drum-a-thon” for an organization dedicated to supporting families of children with serious heart conditions. In this event, a man named Steve Gaul drummed (on a full drum set) nonstop for over 122 hours, breaking the Guinness Book record for that activity and raising funds for the organization.

2. Charitable Objectives and Beyond

When I asked –thon organizers to describe their events, they often started with some explanation of their organization’s need for fundraising. Of the 25 event organizers I interviewed, 15 of their events involved some form of fundraising. Most were hosted by organizations that designed their –thons as part of their annual fundraising goals: the YMCA, Salvation Army, and Habitat for Humanity being some of the nationally recognized charity names. Every –thon was organized on behalf of a named group – there were no individual organizers staging a –thon without an imprimatur that speaks for multiple voices.
But while charity is an overarching motivating factor for the organizers I interviewed, it cannot be said to be the only or even dominant one. In many instances, the –thon was designed for participants to simulate or experience otherness. For example, Redwood Gospel Church’s “Live-in-Your-Car-a-thon” was a fundraiser, grossing over $11,000. But it was also designed to educate and train those who participated. Eric Sangervasi, the Development Officer for the Church, told me that the event was unlike golf-a-thons and walk-a-thons they have used in fundraising campaigns before. Those, he said, were about fun and didn’t “change or challenge” anything. The Live-in-Your-Car-a-thon, however, allowed participants to “put yourself in the shoes” of people who experience homelessness and need to live in their cars.

In other events, the design of the –thon is an outgrowth or extension of an activity that is encoded with meaning that transcends the local and physical moment. A “Walk-a-thon” for First Steps of Jasper County, an educational preparation organization, was designed as a memorial to a member of the community who was known to walk for exercise every morning at the track where the walk-a-thon took place. In other cases, the encoding of transcendent values of the collective activity is even more obvious, like the Prayer-a-thon held at the First Baptist Church of Panama City, FL that organized church members into formations to pray for various school districts at the start of the academic year.

It is possible to typologize the forms of the sampled –thons even further. Some can be understood and experiential, meaning they are designed to influence the participants as they engage in the –thon’s activities. The Fast-a-thons held in Chicago and
Boston for non-Muslims to experience the ritual of fasting during Ramadan is a good example of this form.

Another kind is the relay –thon, where collective activity and duration is designed around the sequential sharing of continuous action and performance duties. The Piano-a-thon at the Bountiful Davis Art Center that featured 88 continuous hours of piano playing by a team of performers who signed up for 10 minute playing periods is representative of this kind.

These forms have a more complicated relationship to the charitable drive than one might think at first blush is the dominant motivating force in –thon events. Often these kinds will incorporate a charitable element – and organizers will rely on speech about charity when describing their event to outsiders – but –thons are also designed to impact participants, to help communities apprehend the often-illegible bonds in their communities, and contribute to an often uninterrogated assurance that group formation is determined by an ethical imperative to help others.

3. A Familiar Form

In each of my interviews, I made sure to ask organizers about whether they modeled their events on others in their community. I asked whether there were other kinds of –thons they knew about before starting their own and whether they had the success of another marathon in mind when deciding on their planning details.

In some cases, organizers had very specific events in mind. For example, Rana Yurtsever, a Program Director at the Niagara Foundation in Chicago that organized a Fast-a-thon, mentioned a Serve-a-thon event held annually in the city by an organization called Chicago Cares. She knew about the Serve-a-thon because she has worked with the
organization before, but also because it kicks off a spring- and summertime cycle of many –thons around the city. Speaking about the –thon as a form, “In Chicago,” she said, “it’s a thing.”

But most of the people I interviewed could not specify where they had heard about other –thons. They couldn’t locate other instances of the same form. Aubrie Kavanaugh, organizer of a Chip-a-thon to microchip domestic animals in Marshall County, AL told me that she guesses it would be the many Adopt-a-thons around the country she has seen advertised in her work with animal welfare services, but couldn’t say with certainty. “If I’m being honest with myself,” she told me, “the concept of the adopt-a-thon was probably somewhere in the back of my brain and when I was thinking ‘Okay, how do we get people to microchip pets, get their attention, make it positive?’ I think that’s where that reference came.”

Jennifer Geran, the Branch Manager at the City Heights/Weingert Branch of the San Diego Public Library, organized a banned books “Read-Aloud-Read-a-thon” to raise awareness about censorship of controversial print material. When I asked her if there were other –thons she knew about while she was planning her event, she mentioned the Jerry Lewis telethon: “I thought of it [the read-a-thon] as a telethon for censored books.” But as I was ending the interview, she stopped me to make something clear: a lot of the insight about her event was true, she said, but it was not thought that way during the planning or even during and after. “I don’t think we were contextualizing it in an overwhelmingly thoughtful way,” she said. She went on, however, to say that she can see how the marathon form has its own structure, “like a sonnet, it has all the right beats in all the right places.”
It was clear that many organizers had only thought of the –thon as a form during the interview itself, at which point they told me they could see the legibility of the –thon as a form across many kinds of events. Some attributed the latency of the form to a branding mechanism: “-thons” are just catchy.

The familiarity of the –thon form is directly linked to the imprecision its participants have in their talk about their work. Confirming a central complication about ritual communication, organizers demonstrate that speaking about their events is only a partial method of accessing what the rituals attempt to accomplish. Thus the familiarity of the –thon is one of the most important preliminary insights about marathons of all kinds and allows me to hone and further develop a methodological design in the other chapters that will put on display the many cogs in the wheels of the larger case studies I’ve chosen for close examination than these interviews alone allow.

**Selected Cases: Structure of the Project**

While the data above help us understand some of dynamics at play in the diffusion of –thons across the U.S. each week, these interviews only offer a quick, contemporary, and partial cross-sectional glimpse into the ritual work of marathons. Thus I have selected a number of specific, popular, and telling cases through which to understand how and why Americans organize –thons.

**Telethon**

Though strict periodizations are difficult to establish when dealing with as malleable a form as marathons, in general we can see telethons as some of the earliest major American –thon events. They were also the most popular and widely viewed. The first chapter begins with the telethon for these important reasons, but also because it is a
kind of glass flower of the dynamics under consideration: the telethon demonstrates some of the most important features in ritualizing ideals of ability in the U.S.

Evidence in this chapter comes from over 150 hours of archival telethon footage from the inception of the form in the early 50s through to its decline in the late 90s and early 2000s. I focus on the Jerry Lewis Labor Day Telethon, a salient program and charity in telethon production.

Through my analysis, I show that the telethon’s management of ideas of endurance, mediated and distributed to at-home viewers, enacts meaning about the virtue of able-bodiedness, above and beyond the specific images of disability that the telethon produced (and that has almost exclusively been the focus of disability advocates’ contestation of the genre).

Dance-athon & Walk-athon

Inspired in many ways by the popularity of the telethon (and even in some cases featuring as part of telethons), the dance-athon and the walk-athon became new public and popular –thons. Beginning in the 1970s, dance-athons and walk-athons became reliable fundraising tools for charity and civic organizations, especially on college campuses. Both draw from earlier forms in the 20th century, notably the dance-a-thon’s harkening back to Depression Era stunts of weeks-long flagpole sitting, ice block sitting, and dance marathons as entertainment spectacles.

I first focus on this civic reprise by focusing on an important and convenient proxy for the many dance-athons that began in the latter decades of the 20th century and continue today. Horace McCoy’s novel They Shoot Horses, Don’t They? was originally published in 1935, capturing the spectacle and tragedy of dance endurance during the
Great Depression. In 1969, the novel is adapted for film and directed by Sydney Pollack, eventually earning 9 Oscar nominations. I offer a close reading of the film to situate it within a new political and cultural climate.

I then pair this reading with a content analysis of newspaper and periodical mentions of “dance-athon” and “walk-athon” throughout the 1970s to uncover the ways the forms were transformed into a vehicle for civic fundraising. As new discourses about healthy publics took shape around the time of the film’s release, dancing and walking became two ritual forms that transformed the emergence of disability as a topic of public discourse (in large part thanks to the popularity of the telethon, as well as the successes of cancer research advocates) from something potentially threatening and disorderly into a manageable category always imagined as eliminable through salubrious collective activity.

Hack-athon

Finally I turn to the most popular contemporary incarnation of the legacies I trace in the other chapters. Hack-athons emerged in the late 1990s as a format for temporally extended performances of hacking, or the process of finding creative technical solutions. The hack-athon condenses a new imagination of the democratization of technology and models new forms of labor after software production. But hacking differs from other -thon activities, placing the body in relation to code in ways that shift how we can understand the role of endurance (and might explain the fact that the hack-athon has, by many accounts, run out of steam). Thus, this chapter has an important role as outlining the meaningful inconsistencies that show us the limits of the -thon form in a digital age.
In this chapter, I report on interview data with disability hack-athon organizers, first furnishing some data about reported key features of this -thon and then exploring the ways that concepts like repair and cure motivate hack-athon work – and may in fact have a tenuous hold on the kinds of embodied experience that previous -thons were able to produce. I find that the hack-athon activates familiar scripts in the *thon mosaic, but in new and different ways.

American Aspirations in Endurance

At the start of this chapter, I outlined the reasons we will trace endurance as a performed feature of -thon rituals, noting that there is an array of options for reporting embodied experiences of temporal persistence. Sweating, sleeplessness, and soreness, among others, are all conditions of what Rappaport would call the “accepting self” that forms the first order of meaningful ritual engagement. But the role of the breath in -thon events takes on particular resonance in the symbolic chamber of -thon activities. In the first place, being out of breath makes it hard to talk, one way we see how bodily characteristics outplay speech alone. But as I will explore here and in the concluding chapter of this work, I see the breath as an expansive analytic for understanding the richness and depth of endurance in American culture.

–Thons, as I see them, place various positive values on the state of being out of breath, literally or figuratively. –Thons often signal a virtuous refusal to quit, a commitment to going on and on, relying on demarcations of time to signal something beyond time itself about the importance of trying and trying again. –Thons are American moments of endurance, through which we lay bare shared aspirations about what it means to be healthy, normal, and active participants in society. What strikes me most is how
they crystallize American ambitions, certain steadfast longings for the capacity to move or be normal or stay, however improbably, autonomous. –Thons are about aspirations.

In addition to signifying a certain kind of desire, “aspiration” is something more fundamental, something essential, of the body. To aspire is both to hope and to breathe.

If disability can be understood in a model of universalizing difference, as Eve Sedgwick would say, then perhaps we can understand breathing as a complementary analytic, in a model of universalizing sameness. Imperatives to “take a deep breath” or “hold your breath” betray the liminality of aspirational in/voluntariness. For many, breathing is the required bodily function that you can nonetheless control to a degree. Yet marathon rituals often assume everyone can control their breath together, the same way. And the extent to which an individual performs effortful aspiration in the presence of others determines how the group marks collective progress and simultaneously distinguishes participants from one another.

I’m thinking of which aspirations are sanctioned, who can aspire to something, and who can aspire at all. I’m thinking of breaths that are easy or held, short, choppy or drawn out. I’m thinking about whose breaths we hear, whose breaths endure, who can take a deep breath. I’m thinking about whose breaths are snuffed out.
I’m thinking of the work of endurance artist William Pope.L, whose project called “eRacism” involved him crawling unfathomable distances, often in a suit, pushing a potted flower. I’m thinking about how his crawls evoke a crip aesthetic of temporality, how similar they seem to the famous Capitol Crawl of 1990 when disabled activists got out of their wheelchairs and climbed the steps of the Capitol building, steps that represent American culture’s persistent refusal to build the literal and figurative ramps that will bring disabled people in the front door. I’m thinking of those for whom being out of breath is not a choice, is not healthy, is not just what happens on a morning run. Since being out of breath is so often offered as evidence that one is working hard, what do we make of the bodies marked as socially invalid who can never catch their breath?

Fig. 1.2: Two columns of two images each. On the left, two images from William Pope.L’s eRacism showing a man in a dark suit crawling on concrete. In one image he’s in the street next to parked cars and in the other he is on a sidewalk. In the other column, two images from the 1990 “capitol crawl” protest. In one image, a young girl climbs steps on her hands and knees. In the other, two people crawl up the steps, one going forward and the other backward. The man in the left column is Black and the people in the right column are disabled.
I’m thinking about Eric Garner’s breath, his asthmatic breath that was repeatedly cited as a justification for his death, a racist trope of invoking the pathetic nature of disability as a way to offload culpability from the ones who truly took his breath. I’m thinking of a poem by Ross Gay that reminds us that Eric Garner worked for some time at a parks and recreational center horticultural center,

which means,  
perhaps, that with his very large hands,  
perhaps, in all likelihood,  
he put gently into the earth  
some plants which, most likely,  
some of them, in all likelihood,  
continue to grow, continue  
to do what such plants do, like house  
and feed small and necessary creatures,  
like being pleasant to touch and smell,  
like converting sunlight  
into food, like making it easier  
for us to breathe.  

What of the aspirations that get snuffed out, if they’re registered at all?

The constellation of American values that produce ideologies of endurance in and through marathons are often noted as tests of strength where the unspoken assumption is that any body can try and all bodies are imagined as likely competitors after the fact. But what -thons make natural is the other kind of endurance test, the ones American ideologies of ability foist upon deviant bodies when those bodies cannot or refuse to assimilate.

What we need is a philology of aspiration, a way of conceiving how Jerry Lewis’s breath gets taken as proof of his good work and yet the breaths of the many people on the run from a hypertrophied surveillance state gets taken as justification of inequality.

Marathons are important public performances about aspirations, literal and abstract. What I’m trying to see in them is not simply a particular relationship between charity, disability, and ritual, but perhaps a much larger system that attempts to make visible certain sanctified ways that certain people can take certain breaths while making it impossible, for deviant bodies of many kinds, to breathe.
CHAPTER 2: THE TELETHON

“For those who understand, no explanation is necessary; for those who don't understand, no explanation will suffice.”

—Jerry Lewis during the 1979 Muscular Dystrophy Association Labor Day Telethon

On the evening of April 8th, 1949, one of television's first stars, comedian Milton Berle, asked audiences to tune into NBC the following day to witness what he called a “television marathon.” When he appears on screen, he performs a quick series of jokes before his tone turns suddenly, powerfully solemn. “Ladies and gentlemen,” he says, “seriously for a moment. […] From this theatre tomorrow starting at 12 noon over the NBC network, over WNB'T in New York and the eastern area […] we are going to do a 24-hour marathon television show.” He reiterates: “Right here in this very gorgeous theater, I will be on the television cameras for 24 consecutive hours.” He mentions the motivation for the event only very quickly, noting that “Here in America, we are very, very concerned about our great health.” The big event, he says as he’s about to leave the stage, “is all for the Damon Runyon Memorial Fund,” a foundation established in honor of the American writer and newspaperman who died of throat cancer years earlier.

The show only lasted 16 hours, but it was no less a notable feat. Seated before a battery of microphones as he alternatively answered pledge calls, interviewed entertainers, and begged for viewers’ donations, Berle was staged at the center of the action. But he was not the sole participant, it was clear. He was flanked by an array of

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79 Admiral Broadway Revue, “Hollywood,” first broadcast April 8, 1949 by NBC and DuMont, Paley Center for Media Collection, Catalog ID T:26282.
stage and screen personalities, models, directors, engineers, electricians, and managers. The NBC pageboy tabulating the donation totals left his seat at the adding machine only once. The hundreds of volunteers answering the phones consumed in all, it was noted in the press, over 3,000 sandwiches, 100 cases of Coke, 5 cases of milk, 25 gallons of coffee, 8 pastry trays, 5 giant jars of pickles, dozens of cookies, gallons of ice cream, turkeys, and Chinese dinners in paper cartons. At-home participants, who performed vicariously, donated a stunning $1.1 million. Niles Trammell, then-president of NBC, proudly claimed it was the longest telecast ever made. And it would not be the last.

What made the program such a sensation was not the actual length of time it was on air, but an overall durational intensity. The litany of superlatives used to describe the broadcast in the weeks after its debut would continue to define the telethon genre until its decline in the late 1990s. This unique format, almost as old as commercial television itself, tore through television’s temporality, not for need of spectacle itself but in terms of civic participation: contributing to the “marathon” television broadcast was imagined as a benevolent and selfless act. Telethons became occasions for Americans to operationalize notions of generosity and charity that they used to imagine themselves together as a community. Donation totals, program length, the glitz, and the sentimentality: the over-the-top qualities of the telethon produced a televisual intensity that, as we will explore below, produced broadcasts that were tests of physical and moral health at once.

83 Ibid.
85 There are many reasons for the decline of the telethon, but they are not largely relevant to the focus of this chapter. Briefly, two main causes are dwindling audiences (as a result of market fragmentation as channel options grew) and higher costs of production (after networks no longer offered distribution for free, a result of 1980s deregulation of the communications industries).
Waxing in popularity in the 1950s, telethons became a fixture of the latter twentieth century American television landscape. There were telethons after hurricanes in Mississippi and floods in Illinois, telethons to aid famine and indebted farm workers and assist homeless people, telethons to help young African Americans access higher education, telethons to save the Indiana Pacers from financial ruin, to support a stadium for the L.A. Dodgers, to send the U.S. team to the 1952 Olympic games, telethons to help the Democratic party pay off its campaign debts, among other causes. And of course there were telethons relating to that great kaleidoscope of what Berle called America’s “great health”: for hospitals, mental health initiatives, disease-specific causes, and disabilities of all kinds.

Indeed, midcentury private health charity professionals were the first to introduce the format. The first, most popular, and most innovative telethons were staged by
charities related to disability. For the hundreds of millions of Americans who watched these programs during the latter half of the twentieth century, it was comedian Jerry Lewis’s face and the Muscular Dystrophy Association that would come to mind when hearing the word “telethon.” But before the popularity of Lewis and the MDA, the United Cerebral Palsy Associations, March of Dimes, the National Easter Seals Society, and the Arthritis Foundation all produced standard-bearing telethons soon after the Runyon Fund’s first program.

A central goal of this chapter is to explain how the telethon’s relationship to disability is not merely accidental but reflects deep-rooted ideals of individualism, generosity, and patriotism that are routed through the aesthetics of endurance. I explain how the telethon’s formal features are also conceptual categories that explain how the format enacts cultures of the body, attempting to achieve what we can understand as “moral prophylaxis.” Tracing the formal-analytic features help us explain the telethon’s most important characteristics: its demarcation of benevolent able-bodied participants from invalidated but worthy charitable subjects, a pace and performance of television production that concretizes values of perseverance and vigor, and a constellation of ideas about the body that is both physical and moral.

Throughout this chapter, I insist that to understand the telethon as a powerful mechanism in the maintenance of American ableism, we must focus on performances of endurance and not merely on the content that courses through the frame. Critics of the telethon have largely focused on the way it presents disability as a tragedy, even during

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the emergence of political disability advocacy in the 1970s that sought to undo automatic assumptions about the pathetic nature of disability. But telethons do something beyond simply saying something. Thus, a focus on representation alone leaves the telethon’s most important communicative functions devoid of serious examination. Here I follow analytic innovations in the study of formalized events by focusing on the telethon’s formal “sensible” features that constitute a methodological and conceptual path to its “significata.”

It is through the organization of its form that we can understand how the telethon communicates what its constitutive elements alone (in language, performativity, and materiality) cannot. Ultimately, this approach helps explain how the telethon’s mediation of physical activity gets morally transfigured into alignment with myths about ability.

The quick line quoted in the epigraph – Lewis’s claim that the telethon can’t be explained to those who don’t understand it and doesn’t need to be explained to those who do – turns out to be a profound characterization of the problem that faces the study of the telethon. The telethon’s communication apparatus is complex and unique, combining vectors of mediation but analytically irreducible to any of these alone. When Lewis emphasizes a demarcation between those who can and cannot “understand” the telethon, he is, with a different motivation than mine, signaling the difficulty in capturing this wide weave of elements. But this challenge compels, rather than dispels, the need for analysis, becoming a central part of what Roy Rappaport has said about the singularity of ritual-as-

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94 I am drawing here from anthropologist Roy Rappaport’s study of ritual and, later, a kindred legacy in the study of media events. It is important to note that the analytic primacy of form does not dispense with content. Ritual form, Rappaport has said after Stanley Tambiah, is simply “the arrangement of contents” and thus any idea that form can be decoupled from content is certainly reductive. Roy Rappaport, Ritual and Religion in the Making of Humanity (Cambridge, UK: Cambridge University Press, 1999), 29.
communication: it “is not simply an alternative way to express any manner of thing, but that certain meanings and effects can best, or even only, be expressed or achieved in ritual.”

This chapter seeks to square what Lewis would have as a circle, and in the process illuminate what can only be expressed by the telethon and its contributions to Americans’ notions of dis/ability.

**Telethonology**

Explaining the characteristics that define the telethon form will be central to the conceptual objective of this chapter, but we can begin with a rather broad description as our start. Telethons can be described as live televised events lasting several hours, sometimes for the better part of an entire day, that ask audiences to call a toll-free phone line to donate money to a given civic or nonprofit charity organization. They feature musicians, celebrities, and other notables who appear at regular intervals throughout the program, usually between pre-produced features about the given charity’s good work. Periodically there is a bright shining tote board displaying the running tally of donations, production staff that wanders on and off the stage, emcees who alternatively cry and laugh for hours as they appeal to a giving public, and, in the cases explored in this chapter, disabled people who feature to remind audiences of their obligations to be givers, not-too-too-greedy individualists.

Despite the genre’s longevity, popularity, and capacity to raise enormous amounts of money, the telethon remains an under-studied format. It is barely a footnote in

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Although I don’t treat the telethon as a fully coherent ritual (per my discussion of existing literature in the preceding chapter), I find Rappaport’s innovations in studying formalized collective behavior quite useful for this chapter and will draw on them when relevant. *Ibid.*, 30.
television studies, rarely noticed in media studies writ large, and narrowly investigated by disability studies scholars. A recent monograph by disability historian Paul Longmore is the only rigorous study of the form and his text forms an important foundation for the work in this chapter. Referring to the telethon as a “pedagogic public space” for its capacity to create and then instruct audiences about the meanings of disability, Longmore shows the way telethons fit into the economic and political landscape of modern America. Telethons were, he says, moments when Americans attempted to work through long-standing moral dilemmas about disease, disability, and health. In his tracing of the way the telethon sat in relation to a wide weave of American politics and culture – from private and public health and welfare systems to the birth of cause-related marketing to the growing disability rights movement – he shows how, as he has said elsewhere, the telethon was “the single most powerful cultural mechanism defining the public identities of people with disabilities” in the last decades of the twentieth century.

96 Save a 1977 “descriptive analysis” of the 1977 MDA Telethon by Joseph Lawrence Londino as his dissertation at the University of Michigan, cited throughout this chapter. There is a richer body of literature from quantitative effects studies of telethons, but these studies tend to use the telethon as a methodological proxy for a communication process rather than exploring the telethon itself. See, for example, Mark H. Davis, “Empathic Concern and the Muscular Dystrophy Telethon: Empathy as a Multidimensional Construct,” Personality and Social Psychology Bulletin 9, no. 2 (June 1983): 223-229.


99 Paul Longmore, “Charity Telethons and Disability Activism,” (lecture, Ryerson University’s School of Disability Studies, November 11, 2005), http://www.ryerson.ca/ds/focusBoxes/charity_telethons.html.
Despite the many places where Longmore locates telethons’ influence, he pays rather scant attention to it as one of many intensely physical forms of civic participation that I examine as the –thon form. In order to understand the telethon as an emblematic case in the larger category my dissertation formulates as a powerful cultural mechanism, we can turn to the venerated legacy in media studies that, as I noted in the previous chapter, began with Robert Merton’s 1946 study of the telethon’s most important and immediate predecessor. In Mass Persuasion, Merton seeks to understand the extremely popular and successful war bond drive hosted by Kate Smith during radio “marathons” in September 1943, which garnered about $31 million, or about $4.3 billion today, in war bond purchases.

There are a number of key differences between Smith’s marathon and Jerry Lewis’s telethon, namely that Smith’s was interstitial during a day’s scheduled radio program while Lewis’s formed the program itself. But the similarities are abiding and give us an analytical through-line that leads us to refinement of key questions Merton’s study leaves open, like the capacity for the marathon to synthesize much of its communicative work.

I take up Merton’s focus on what he called the “Gestalt” of the marathon, a term he drew from literature in Gestalt psychology at the time. Perceiving Smith’s appeals together, as a Gestalt that “stands out like a figure against the ground [of usual radio programs]”\(^\text{100}\) allowed him to consider the radio appeals as an aggregate with a climactic structure. It becomes, he writes, “a moving drama, a drama in which the listener himself

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[sic] plays a part.”\textsuperscript{101} Viewers’ donations are sacrificed as a mirror to Smith’s effort, which is sacrificed as a mirror to the soldier’s ultimate sacrifice. Merton lays the foundation of the marathon as a temporal pattern in order to take up social psychological questions about the incentive and reward structures of Smith’s appeals. I find that the telethon is an important and convenient case study we can use to further extend a key aspect of Merton’s analysis: how the marathon’s Gestalt – or aesthetics and formality – relies on a refusal of disability in its centrality of endurance.

Merton explains that part of Smith’s success in her drives relied on the “propaganda-of-the-deed” borne out by Smith’s physical sacrifice. “[T]he presumed stress and strain of the eighteen-hour series of broadcasts,” he writes, “served to validate Smith’s sincerity.” And her sincerity resonated with the bonds’ connotations of blood and suffering in war that, with other formal aspects of the radio marathon’s scripts, produced the “sentiment of symbolic fitness” as a consummate representational circuit. “The act, interpreted as indubitable proof of her willingness to sacrifice, persuaded those who resisted the word.”\textsuperscript{102}

The present study of the telethon inquires further into the way that the body is lodged at the center of marathons’ capacity to activate collective deep feelings. Explored in the sections below, this chapter puts endurance center-stage, as it were, and in so doing proposes that exceptional performances of stamina rely more on the scripts of stamina than on representations of disability.

The telethon is thus instructive within the larger formation of the -thon for the way it directed viewers to ideas of endurance in keeping with- while simultaneously

\textsuperscript{101} Ibid.  
\textsuperscript{102} Ibid., 96. Emphasis in original.
expanding ideologies of ability. It puts on display some of the most important facets of Americans’ insistence on the moral transfiguration of the collective, literally aspirational body. That is, Jerry Lewis’s labored breathing during his sleepless telethon performances coordinate viewers’ vicarious lesser sacrifice of giving as a Gestalt effort. As discussed in the previous chapter, the role of the body in the –thon’s ritual apparatus is a large part of its communicative capacity – and the telethon is an important occasion for us to better understand how it operates.

On-screen telethon participants performed their sacrifice on behalf of assumedly invalidated social actors (people with disabilities) while hailing to at-home viewers who could help redeem the less fortunate while also potentially securing for themselves a future free of the tragedy of disability. Telethon performances of stamina and generosity hinged on distinctions between disabled and nondisabled people that emerge in many kinds of –thons. The assignment of roles to various actor-categories helps illustrate rhetorical and discursive relations that are in play in many –thons, as will be explored below.

There are several other reasons for my choice of it as the first in the series of –thons I study throughout this dissertation. One is its popularity: telethons were the most watched of all –thons. In one of their telethon-related publications, the Muscular Dystrophy Association reported that their 1977 broadcast, coming on the heels of the previous year’s sensational reunion of Jerry Lewis and Dean Martin on stage after years apart, reached an astounding 50.7% of all American households.\footnote{Telethon Topics, October 14, 1977 (New York: Muscular Dystrophy Association, Inc.), 2, qtd. in Lawrence Joseph Londino, “A Descriptive Analysis of ‘The Jerry Lewis Labor Day Telethon for Muscular Dystrophy’” (doctoral dissertation, University of Michigan, 1978), 6.} That rating topped the
combined ratings of five nights of *Roots*, a show that dominated that year’s audience metrics.¹⁰⁴ Two years earlier in 1975, the A.C. Nielson ratings service reported the MDA Telethon reached 82 million people,¹⁰⁵ topping that year’s Super Bowl viewership of 56 million.¹⁰⁶ Ratings of this sort, it should be noted, are ultimately unreliable in capturing viewers’ engagement with something as unique a format as the telethon, since the figures only approximate how many televisions were tuned in and not how viewers watched the content that would often last for over twenty hours. But as I will explore later in this chapter, references to telethons in popular culture give a strong sense that telethons were highly-viewed American media events. Their stature among other –thons is a key reason I begin my study with the telethon.

Archival material in this chapter is varied. There is no comprehensive home for telethon footage, perhaps because the genre confounds archival practices as an interstitial not-news, not-fiction form. However, I was able to view over 150 hours of telethon footage spanning the decades from early 1950s through the 2000s in various media archives including the Paley Center for Media in New York, the Library of Congress’s Moving Image Research Center, the papers of Paul Longmore at San Francisco State University, and the United Cerebral Palsy of Middle Tennessee. Appendix 1A includes a discussion of- and detailed list of the primary source broadcasts I have watched during my research for this chapter, as well as a methodological note about the telethon material available on YouTube. Appendix 1B includes a play-by-play of six hours of one of the

most widely viewed telethons, the 1976 MDA Labor Day Telethon. And Appendix 1C takes the form of an editorial I’ve written urging the MDA to open its archives, which are sealed off from audiences and researchers.

In addition, I rely on a large cross-section of print media coverage of telethons, mostly from major national newspapers and periodicals. The Television News Archive at Vanderbilt University has catalogued a number of instances of news coverage of telethons, useful for the way telethons “make news” by dint of their unusual length. I have made extensive use of historical newspaper databases to collect commentaries from television and cultural critics throughout the run of the telethon’s popularity.

While my analysis looks at the telethon as a coherent form among the many organizations that produced them, the Jerry Lewis Muscular Dystrophy Telethon is a particularly important program among the rest. It was the most watched, raised the most money, and garnered the most attention from other media sources. The MDA also innovated the form in ways that helped it propagate across all kinds of organizations and causes, including the alternation of the national broadcast with content produced by the particular stations in the “Love Network” that localized the donation appeals. I see the MDA production as a standard-bearer of the telethon form as a whole and thus it makes for a useful chief case.

In the analysis below, I start with the telethon’s frame of the battle and race, which I argue has a defining attribute of endurance. This frame sets the stage, sometimes literally, for intensely physical performances. Through the telethon’s mediation of

107 This is a perspective shared by almost all cultural and scholarly critics of the telethon as a general format. “In the late twentieth century, nearly everyone who talked about telethons – whether they were defenders or critics, including most disability rights activists – focused on the MDA telethon,” Longmore writes in his introduction. Longmore, Telethons, xiv.
endurance, I argue it attempts to produce – with mixed success – its chief function of 
*moral prophylaxis*. These formal categories are also conceptual ones in that they describe 
the most important interchanges in the telethon’s communicative capacity. The following 
three sections lay out these categories in turn, simultaneously describing and explaining 
the telethon as an event form.

**Out of Breath**

Over the years, Lewis’s opening acts routinely featured one or another out-of-breath acts. In 1992, he emerges on stage for the first time tap dancing. He taps for so long that when he picks up the microphone he jokes that 911 is on the way as he tries to regain his breath.108 In footage of rehearsal in 1989, Lewis is seen practicing with Sammy Davis Jr., donning one the various sports jerseys he wore throughout the day. After a few moments he yells over the music, “Ah shit! I run out of gas!” He tries again for a few seconds, then stops and grabs his chest. For a while after, he hangs a towel around his neck as he goes over details of the upcoming show with his staff.109

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108 “1992 MDA Telethon,” Paul Longmore Papers, San Francisco State University, Box 140.
Lewis’s penchant for tap dancing makes sense as a telegenic combination of sight and sound that aligns nicely with the requisite performance of effortful endurance to persist throughout his hours and hours on screen. As one obvious way the telethon made itself in the image of fitness, its hosts needed to show how hard they, and the teams of producers and volunteers, were working. Successful emcees were those who were sometimes literally “running” the show. Dalton Walker, who hosted a 1953 telethon for the Lighthouse, an organization that assisted the blind community, was panned by the television critic for *The New York Times* as “not quite the ebullient and extroverted personality needed to sustain excitement over such a long stretch.” Even the studio audience, he said, was “lethargic.” This criticism of early telethon performance indicates just what they could never dare do: take too long a breather.

In this section, I linger on the endurance performances of the telethon host in order to examine the how performances of endurance are central to the communicative structure of the telethon. To quote a crucial point from Rappaport’s study of ritual behavior that helps describe the telethon’s work: “Unless there is a performance there is no ritual.” Here I argue that the hallmark feature of telethon performance is endurance, out of which emerges a number of other characteristic aesthetic features that help explain the legibility of the format.

Many of Jerry Lewis’s monologues made clear the duties of the host as central to an otherwise cluttered televiusal array. One of the earliest and most trenchant critiques of the telethon was of its spectacular nature, that the format swung with abandon between

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111 Ibid.
the lachrymose and the laughable, demeaning the true urgency in charity appeals.

“Normal human values,” New York Times television critic Jack Gould wrote in 1953, “go slightly askew on the telethon. If the spectacle is excused in the name of helping a commendable charity, this does not make it edifying.”

Paul Longmore contextualizes this critique within Americans’ “traditional moral economy” that eschewed the kind of publicity around charity donation that the telethon invited. “Age-old Jewish and Christian admonitions,” Longmore notes, focused on giving anonymously, which is one reason 1920s Jewish immigrants lamented the “great to-do about charitable affairs” in the U.S. But as traditional elitist charity was democratized in the twentieth century and professional fundraisers pioneered mass charity as a business, Americans increasingly celebrated the publicity of giving. Desires for upward social mobility that had manifested in conspicuous consumption, Longmore argues, channeled into “conspicuous contribution.” Telethons’ celebration of individuals’ donations – names of donors read aloud at regular intervals – were part of a uniquely American class-inflected change in the role of charity during the middle- and latter twentieth century, which might also help explain why patriotic aspects like the national anthem and the American flag were so prominently featured during the broadcasts. Critiques like Gould’s about the insincerity of publicized donation insisted on the moral economy of giving that the national community was collectively calibrating at the time.

113 Gould, “Television in Review.”
114 Longmore, Telethons, 75.
116 Longmore, Telethons, 75.
Countering critiques like this were those who found telethons, Longmore argues, spoke to “a general fear that Americans had lost the sense of moral community they believed had once bound them to one another,”\(^\text{117}\) a sentiment reflected in public opinion surveys from the 70s through the 90s.\(^\text{118}\) Telethons, in this way, continued what historians of philanthropy consider to be a cornerstone of American political philosophy by placing philanthropy outside the state apparatus and designing it as a system of *voluntary* giving. In fact, several mid-century tomes celebrating the living tradition of voluntarism as a uniquely American political virtue focused specifically on private health charities as a model for free and democratic society.\(^\text{119}\) Telethons helped formalize a shift from earlier 20th century philanthropy into the emerging industry of nonprofits in the U.S. by stressing the centrality of voluntarism to enormous audiences each year.\(^\text{120}\)

Longmore argues these dynamics make the telethon a uniquely American tool for audiences to grapple with changing national politics. For one, Longmore writes, “telethons conveyed implicit political messages about the American system of provision for public health and welfare.”\(^\text{121}\) Milton Berle’s claim that Americans are “very, very concerned about our great health” on the first telethon in 1949 also indicates how this concern is perceived and voiced as distinctively American.

As will be discussed below, this includes the way telethons were offered as a kind of health insurance during decades when public and private healthcare grappled with

\(^{117}\) Longmore, “The Cultural Framing of Disability: Telethons as a Case Study,” 505.  
\(^{118}\) Longmore, *Telethons*, 8.  
\(^{121}\) Paul Longmore, “The Cultural Framing of Disability: Telethons as a Case Study,” *PMLA* 120, no. 2 (March 2005): 505.
cutbacks to federal and state budgets at the same time that federal legislation and regulation allowed for increases use of managed care programs.\textsuperscript{122} Throughout this time, people with disabilities were the most likely to depend on government insurance \textit{and} the most likely to be uninsured.\textsuperscript{123} In addition, telethons explicitly celebrated and modeled corporate philanthropy as big business found charity work as insulation against public criticisms about self-interest and avarice, exemplified in the corporate philanthropy of the nursing home industry during repeated scandals of neglect and abuse in the 80s.\textsuperscript{124}

This returns us to the role of the telethon’s propaganda-of-the-deed. The performance of endurance circumvented the problems of insincere publicity by enrolling individual donations in a circuit of symbolic fitness, which in turn condensed long-standing political traditions about the benevolence of voluntarism. If Lewis could \textit{show} his endurance on screen instead of merely talking about it, audiences could mirror the work, as Gestalt, in their giving and thus the publicity of their giving became an occasion for group value affirmation. The mediation of the telethon thus connected the out-of-breath telegenic body to the at-home viewer who experienced the giving as a vicarious sacrifice mirroring Lewis’s.

\textsuperscript{122} Longmore, \textit{Telethons}, 25; Peter Fox and Peter Kongstvedt, “A History of Managed Health Care and Health Insurance in the United States,” in \textit{The Essentials of Managed Health Care, 6th Ed.} (Burlington, MA: Jones and Bartlett Learning, 2013).
\textsuperscript{123} People with major disabilities were more likely than nondisabled people and people with minor disabilities to rely on government insurance and people with minor disabilities (often employed) were more likely than nondisabled people and people with disabilities to be uninsured because their financial resources disqualified them from government assistance but their disability-related living expenses were too high to cover without assistance (especially given widespread insurance discrimination against disabled people). Longmore, \textit{Telethons}, 23.
\textsuperscript{124} \textit{Ibid.}, 37.
In 1979, Lewis began a segment by attempting to enact this embodied circuit of meaning. He ended up explaining many of the telethon’s stated goals and how the host’s performance of endurance is what ties them together.

You see we’re tight-rope walking. You’re living with a double edged sword. Because we want to appeal to you and get you to ring the phones, then we have to give you a break and entertain you to keep your interest, then we have to get back down to reality, then we have to come up on a high, then down to a low, [Lewis lunges in various directions with each emphasis] then I got to run over and check and see is the game plan working, then I got to be sure Rocky [the 1979 MDA poster child] is secure. I got to be sure Bob [Samson, a disabled Vice President at United Airlines who had just appealed to at-home viewers for donations] has heard what he wanted to hear, I got to run and see that all the celebrities are at least greeted, I got to run over here [actually running, now in full strides] and find out are we doing okay. All of that stuff is fine, but now we don’t have a lot of time [gestures to the clock/board]. Now we’re gonna give you a little entertainment so I can stand over there [pointing off camera] and go [pants, out of breath] for a minute.125

In this rich monologue, it is Lewis’s literal running between the many parts of the show that ties them together. The panting Lewis pantomimes illustrates the physical and conceptual fitness that constitutes the telethon’s moral and communicative center.

**Script of Endurance**

We can thus see how endurance is a crucial performance for the telethon’s script of moral fitness. By “script” I refer to an analytic offered by theorists of media events Daniel Dayan and Elihu Katz who pick up Robert Merton’s fascination with the possibility for media to manage public feelings through the staging, mediation, and perception of events. Scripts, Dayan and Katz writes are story forms that “determine the distribution of roles” in events and “the ways in which they will be enacted.”126

The script names similar work to that of the frame, a rich heuristic in media studies that emphasizes what Gregory Bateson once called the “signal about signals” that

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“organizes, differentiates, and assigns value to the various objects and performances that pass through it.” Erving Goffman defines the frame as a basic identifiable element of “principles of organization which govern events – at least social ones – and our subjective involvement in them.” Analytically, frames are useful in identifying event features and the organization of experience within them.

But the frame alone cannot explain the unique features of the telethon. A theatrical frame with a stage, curtains and all, and live audiences don’t entirely capture the complexity of the event, since it would be analytically impossible to distinguish the telethon from any other live televised event (especially those in the early days of television that routinely took the form of a live theatrical broadcast). It is the telethon’s unusual length that sets it apart as a media genre and as a civic event. But again, the length alone is insufficient to explain the structure of the format since the “television marathons” of a single pre-produced show that emerged in networks’ programming would fall under the same analytic category. There is stronger emphasis to be placed on representational order derived, as we have been proposing, from the management of stamina through the scripting involved during these live events.

Dayan and Katz propose three kinds of scripts in media events derived from Weber’s typology of authority: the contest, the conquest, and the coronation. Coronation, they note, are “all ceremony”: homecomings, funerals, and literal coronations are good examples of the category. If the coronation script occurs on the telethon, it is only

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127 It is important to note, however, that the existence of the frame itself does not guarantee there will not be “frame disputes,” to use Goffman’s term. Interestingly, the telethon’s race frame was rarely disputed in the anti-telethon activism that is discussed below. That activists opted to contest the content and not the frame might be one reason their protests failed to more seriously halt the success of telethons through the 90s and into the 2000s. For Goffman on frame disputes, see Erving Goffman, Frame Analysis: An Essay on the Organization of Experience (Cambridge, MA: Harvard University Press, 1974), 322.

128 Ibid., 10.
employed sporadically, perhaps when a 1976 pre-produced segment about the ribbon cutting ceremony of the Lewis Institute for Muscular Dystrophy at UCLA. More commonly evoked are the scripts of contest and conquest.

“Contests,” Dayan and Katz write, “are a training ground for the construction of social institutions based on rules.” In contests like the game show, beauty contest, or election, the rules are well-known and familiar, which allows for the electric quality of the play-element. The “stepping out of everyday life” involved in contests heightens the drama about who will emerge victorious.

Conquests, on the other hand, tend to be less rule-dependent. They emphasize hero-myths, pitting an individual against natural, formidable opponents. Egyptian President Anwar Sadat’s 1977 pilgrimage to Israel is Dayan and Katz’s chief example. Rules, in conquests, are far less legible and the drama of the event derives from the uncertainty about whether a hero will prevail against substantial odds. Dayan and Katz are quick to note that these scripts are wont to overlap and change over time. The telethon is particularly instructive of these vicissitudes because it combines many elements of contest and conquests (and, as noted, occasionally coronations).

In fact, the telethon can be understood as an important object lesson in the conceptual links between the contest and the conquest. The conquest often involves matters of life and death while the contest deals with matters of symbolic life and death. In the telethon, we see both at once: muscular dystrophy stages the conquest of disabled figures whose lives are framed as hanging in the balance of the program while the ticking clock and donation totals stage the contest of the symbolic life or death urgency.

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Sacrifice is a salient thread that connects conquests with contests. As noted above, telethons design a Gestalt process of sacrifice that enrolls various kinds of participants in vicarious performances linked to on-stage actors. Sacrifice helps us understand the heft of the telethon ritual because it makes endurance *generative*. The most sustained scholarly attention to this process is Carolyn Marvin and David Ingle’s study of the American flag. The periodic bloodshed of war, they argue, is in fact not merely about loss, but about the re-creation of group boundaries, a process Marvin and Ingle call “creation-sacrifice.”

From sacrifice we discover some of the most transformative and potent ritual dimensions of American patriotism. Though bodies in the telethon are not covered in blood, the capacity for symbolic sacrifice to bind individuals in common pursuit demonstrates the centrality of sacrifice in the conceptual framework that helps explain the telethon’s potency.

**The Battle**

In the final hours of his 1979 telethon for muscular dystrophy, Jerry Lewis delivered this monologue about how he is “fighting for our lives by the clock”:

I don’t like to be succinct about it. We’re dealing in life or death. But I’m also fighting the clock. It doesn’t understand. The clock has no emotions, it has no feelings. It just has seconds and hands. It doesn’t even wave with its hands. It just keeps turning. And it’s fighting me. I haven’t got the time to deal with that. I can’t even confer with it. It’s starting to steam me. It keeps moving and it’s attacking my energy system. So if you don’t pick up the phone and help me with these numbers, if I strike out, it ain’t gonna be all that bad, ‘cause that’s pretty respectable [pointing to tote board] but it’s gonna be less than last year. If we come up less than last year, here’s all of the cop outs: the economy, inflation, if we had another president and all of that garbage. That’s a cop out. It’s your fault and it’s mine.

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Casting the clock as devoid of affect is important for the contract Lewis draws up with the audience. Because the clock cannot understand the supposed tragedy of muscular dystrophy, it is the combined effort of Lewis as the on-screen show runner and the audience as the donating public that has the capacity to fund the research that will end the diseases. The clock, in this case, helps Lewis condense an invisible enemy that he, and “we,” Lewis emphasizes, are fighting in the battle stage of the telethon.

In instances like these, we can see how telethons were scripted as battle. Sometimes their militaristic elements were highlighted. Sometimes their marathon or race-like elements were emphasized. But specifying the components of the battle – what is being fought and what constitutes the opponents – is not easy given the transformation involved in what Erving Goffman’s would call the process of “keying”: the “set of conventions by which a given activity, already meaningful in terms of some primary framework, is transformed into something patterned on this activity but seen by the participants to be something quite else.”

The primary framework, in the case of the telethons, is a fundraising entertainment event. But it is keyed as a battle.

When the Mayor of Honolulu designated Labor Day in 1927 as “Jerry Lewis Day,” he cited Lewis’s “21-year battle against dystrophy.” The full scope of talk about the telethon as a “battle” against MD is far too frequent to list here; it was a common refrain to hear the telethon cast in these terms whereby the program was up against the formidable but nonetheless conquerable enemy of disease. The disability of muscular

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133 Goffman, *Frame Analysis*, 43-44.
dystrophy is the enemy that produces the oft-heard team-talk about the most important goals and functions of the telethon.

This script is similar to the one used by Kate Smith’s in her war bond drives, couching the urgency of bond purchases as an extension of the war effort itself. But on the telethon, talk about the enemy has the added complication of describing the enemy as a congenital disability, nowhere located except in the dystrophy of muscles in its “victims.” The battle against disease and disability is therefore manifest only in the bodies of those on the line, which necessitates the arsenal of medicine (doctors, nurses, physical therapists, mobility aides, institutes, and so on).

In the midnight hour of the MDA’s 25th anniversary telethon in 1991, Jerry Lewis delivered a short monologue about the purpose of the fundraising event. He stresses a number of times that neuromuscular disease “strikes” without discrimination, “anyone, any time.” “We know of cases,” he says, “where beautiful children went to bed at night – healthy, perfect in every way – and woke up the next morning and had [a] neuromuscular disease or they had muscular dystrophy and they couldn’t walk.” What the telethon asks, he explains, is to help so that “it doesn’t happen to you or yours.”

Similarly in the mid-70s, Jerry Lewis directed a vignette that aired on many of the MDA telethons. In it, MD is personified by an actor who recites a haunting monologue about threatening the figure of the healthy child.

Let man hurl himself into the galaxies and take snapshots of the moon, but down here on this earth where I prowl, he is still unable to find a cure for this scourge of little children. For I am muscular dystrophy, the hater of people, especially children, and I dare you to stop me. It will take more

money, more science and more love than you have yet been willing to give. Yes, I am muscular
dystrophy. I hate people, especially children.\textsuperscript{136}

Nightmares like this help make legible the telethon’s battle opponent, using the healthy
child to focus the effects of the disease that the telethons sets out to vanquish.\textsuperscript{137} In these
moments when children, often the annual poster children for the MDA campaigns, are
presented as a stand-in for the future itself, we see how the battle opponent of MD
attempts to produce group cohesion by linking the interests of these children with
everyone else participating and watching. Telethons promise a time without disability if
participants step up to the role they are called to.

While the telethon’s contest and conquest scripts involve sacrifice, here we see
how they might also rely on a powerful ballast: fertility. Lewis often ended his telethon
broadcasts with teary renditions of “You’ll Never Walk Alone” from the 1945 musical
Carousel. Deputizing himself as the conduit between the disabled beneficiaries of the
MDA and the large vicarious community of givers, Lewis seeks to grow the community.
It is no accident that he calls the disabled poster children his “kids,” thereby imbuing
himself with the paternal promise of rearing them into fertile adults. Telethon children are
thus key not only as the object of participants’ symbolic sacrifice, but as the possibilities
for a fertile future.\textsuperscript{138}

\textsuperscript{136} Bud Schülberg, “I Hate People” (published by Muscular Dystrophy Association, Inc.), 1974, qtd. in
Londino, “A Descriptive Analysis of the ‘The Jerry Lewis Labor Day Telethon for Muscular Dystrophy,’”

\textsuperscript{137} Here I am talking about the cultural figure of the Child, the one whose future is often invoked as a stand-
University Press, 2004), 86. The Child as the natural inheritor of the future produces a number of powerful
discourses about the need for safety and order, as, for example, in the way crises of family structure are
often discussed in terms of potential harm to the children, See See Lauren Berlant and Michael Warner,

\textsuperscript{138} Carolyn Marvin and David Ingle’s study of the American flag helps us see how fertility can act as an
essential obverse of sacrifice: though the flag is readily understood in terms of sacrifice, the American
public also seeks recombinatory mechanisms for when, as they write, “the magic wears out.” Regeneration
becomes a key process following ritual sacrifice that redeems the community from its proximity to death.
In order to play the paternal part, Jerry Lewis often keyed himself as the ascetic protagonist in the conquest against the formidable opponent of MD. We can see this most readily in middle-of-the-night telethon programming, since it is the night and the emergence from the night that is presented as a key obstacle in the endurance of the marathon. The night in the telethon represents one of the most intense hurdles in the form of temporality that is constructed through the other aspects I highlight in this chapter.

The bold and persistent presence of the able-bodied host before, during, and after the nighttime, together with fear appeals and the performance of endurance, helped establish the telethon’s morally valorous purpose. Lewis said so explicitly in his 1989 broadcast:

You've seen other telethons where the host goes to sleep at midnight and comes back at ten in the morning refreshed. That's not a telethon. You're supposed to be there and let your audience wonder whether you're going to make it or not [...] If I lose my throat in the twelfth hour, I'll go like a bastard for the next twelve. If it happens, it happens. If I get hurt—you know, what do we do if I get hurt in the fourth hour, if I fall into the pit? You can bet your ass that the show will go on, and I'll be there. I may be sitting. I may be in a cast, but nothing’s going to stop me from finishing it.\(^{139}\)

Lewis said something similar during rehearsal the same year. Asking audiences to set their alarm clocks for 3 a.m., he stresses that he stays up the full 22 hours, unlike other telethon hosts. “No food, no water, just working for you,” he says to the laughter of the studio audience. But it isn’t far from the truth according to telethon director Arthur Forrest. Professing that he nor Lewis ever took pills to stay awake, he claimed in 1974, “Jerry and I have an absolute lack of hunger. We just never eat. But we do consume an

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\(^{139}\) Qtd. in Longmore, *Telethons*, 67.

For more on the theoretical basis of fertility as a dimension of American patriotic rituals, see Marvin and Ingle, *Blood Sacrifice*, 215-311.
enormous amount of beverages, cokes and iced tea and water. We just never think of eating.”

When on-stage telethon participants discuss sleep or other forms of rest, it is done with this kind of script to emphasize the need for the able-bodied altruistic figure to endure the race. 1953 United Cerebral Palsy Telethon host George Jessel, for example, was described as taking a break during the night only so he could brush his teeth. At the conclusion of the 1977 show, Lewis proudly announced in his final monologue that he had set a personal record for consecutive sleepless hours, up from 76 hours the year before. He had entered his 91st hour without sleep, he said, and was looking forward to the 7-hour post-production meeting still to come. Lewis did eventually start sleeping during the telethons, for lengths of time that increased in the late 1990s. Yet when any person on stage is described as leaving the broadcast for a period of time, it is an absolute necessity. That the number of viewers dwindled considerably in the middle of the night is besides the point; that the show went on without a huge audience is what makes its reappearance in the morning all the more meaningful.

While Lewis often figures himself as the conduit for the telethon’s battle, at other times we can see that the battle against MD staged on the telethon is meant to be an extension and collective effort of the individual “battles” people with MD wage on their own, in everyday life. Of the few clips the MDA has released publicly of pre-2000

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142 Qtd. in Londino, “A Descriptive Analysis of the ‘The Jerry Lewis Labor Day Telethon for Muscular Dystrophy,’” 159.
143 The lowest viewing period for the MDA Telethon, for example, was between 2 and 8 a.m. Londino, “A Descriptive Analysis of the ‘The Jerry Lewis Labor Day Telethon for Muscular Dystrophy,’” 153.
telethons, one is called “Hulk Hogan and Jerry Lewis” from the 1987 broadcast. Hogan emerges to raucous cheers from the crowd and, on his way to the stage, gives a hug to the disabled MDA poster child that year. He then takes center stage with Lewis, rips off his shirt, and proceeds through a number of body-builder poses. It is in the proximity of Hogan’s machismo in relation to the quintessential representation of disability (the poster child) that we can glimpse the warrior image at work: Hogan and the child are together imagined as warriors, the former for his unusually strong physique and the latter because he is imagined to be a survivor of the assumedly painful, if not all together miraculous triumph over the adversity of death. It is the assumed hardship and suffering of people with MD that informs the telethon’s battle-talk.

![Fig. 2.3: Hulk Hogan bends over to hug the 1987 MDA post child, in a wheelchair, on his way to the stage. On stage, he reveals his bare chest and flexes his biceps. Hulk Hogan and Jerry Lewis (1987) – MDA Telethon,” YouTube video, 2:28, posted by MDA Telethon, Sept. 17, 2016, https://www.youtube.com/watch?v=s1234iYVWQg.](image)

This example helps illustrate how hosts often shared responsibility for their battle performances with acts booked for their intense physicality. The 1997 MDA broadcast featured a troupe of stunt basketball players, called the Dunking Devils, who used a

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trampoline to perform increasingly daring slam dunks to the gasps and awe of the studio audience.\textsuperscript{145}

In 1988, the MDA telethon featured nine young men of the “Desert Dash” cycling team riding through the night from Los Angeles to Las Vegas to appear on the broadcast.\textsuperscript{146} In 1976, fresh off her gold medal performance in the Olympic decathlon, Caitlyn Jenner appeared on screen to talk about the struggles of MD and the urgency to donate, after which Lewis praises her prowess in the Olympic Games. Through these acts, hosts could pass the baton to professionals to maintain its vigorous energy. The headline of a 1953 review of the United Cerebral Palsy telethon captures just what these sporting bodies helped illustrate: “Mostly It Takes Stamina to Handle a Telethon.”\textsuperscript{147}

This “stamina” signals that the telethon’s battle has a unique temporal extension. The exact length of the telethon broadcast often varied, but the durational intensity remained the same. As mentioned above, the fact that Milton Berle was on camera for 16

\textsuperscript{145}“1997 MDA Telethon,” Paul Longmore Papers, San Francisco State University, Box 140.

\textsuperscript{146}In Longmore’s astute analysis, these instances can be linked to the cultural value of bodily control that sociologists of the body have noted (without, curiously, seriously considering the analytic value of centering disability in these discussions). “In the historical moment when the disability rights revolution was making people with disabilities an increasingly visible public presence, American culture was placing unprecedented emphasis on the need for physical and bodily control.” Longmore, Telethons, 124-5.

\textsuperscript{147}John Crosby, “Mostly It Takes Stamina to Handle a Telethon,” Washington Post, December 3, 1953, 43.
hours during the first telethon when he had originally announced he would be on for 24
did little to discredit the attempt because even 16 hours of programming was considered
herculean itself.\textsuperscript{148} When Jerry Lewis started his broadcasts, he would often proclaim
they would last 20 hours, but in the end would last 21 or 22 hours.

This extreme temporal extension is not measured by time alone, which helps
explain why the variability of the broadcast length each year is not a widely-discussed
feature of the race. Use of time is measured and made meaningful by the called-in
donations from at-home viewers, making the program interactive with the public that it
hails to as penance for an otherwise over-zealous commitment to individualistic
accumulation, as Paul Longmore has argued.\textsuperscript{149}

There are other moments when Lewis specifies that the telethon is a specific kind
of battle: a race. In 1957, he began the broadcast on the street outside the Roosevelt Hotel
on 45\textsuperscript{th} Street in New York City. He cues a marching band in parade formation and leads
them inside. A number of cameras bounce along, struggling to keep up. In the lobby
outside the hotel’s theater, onlookers applaud and cheer in two lines making up the route
to the stage. As Lewis ascends one of many staircases, he says “I’m already tired and I
didn’t start yet!” He wends his way through the aisles of the theater and finally lands
under the spotlights, his arms akimbo and his chest heaving. “I want to take this
opportunity to thank [one of the producers] for his very clever idea,” he says of this
opening act. He pants audibly and tries to steady his breath. “Terrific. He should have got
John Landy for this,”\textsuperscript{150} he jokes, referring to the well-known Australian runner who was

\textsuperscript{149} Longmore, \textit{Telethons}.
\textsuperscript{150} “The Jerry Lewis Thanksgiving Party 1957,” first broadcast over NBC on November 30, 1957, Library
of Congress Moving Image Research Center, Catalog ID: FCB 8635.
the second person to break the four-minute mile in what was called the “Race of the Century” in 1954. Over a decade later, Lewis opens the telethon again as the start of a race. This time, in 1968, an announcer says “There are 19 hours to go and the going starts now!” On stage, Lewis sounds a fog horn, complete with a small puff of smoke.  

Thus the race script stages the telethon as a temporal passage through which all participants (on stage and at home) are attempting to race through. This combination of contest and conquest scripts helps explain how the telethon produces its drama, stakes, and stated transformations of participants.  

Though battle-talk in the broadcasts is about a particular set of diseases, the larger enemy-category is not muscular dystrophy itself but disability in general. That the telethon is scripted as a battle against the supposedly pathetic quality of being disabled connects it to a long history of representations of disability as problematic and atavistic of the human form. These eugenic histories are perhaps most condensed in the Supreme Court’s 1927 decision in Buck v. Bell to permit the compulsory sterilization of people with intellectual sterilizations. In his famous majority opinion, Justice Oliver Wendell Holmes wrote that “three generations of imbeciles are enough.” As historian Laura Lovett has chronicled, “Fitter Families for Future Firesides” and “Better Baby” contests started in the 1920s to model a modernist promise for scientific control. And while the telethon’s quest for a cure for muscular dystrophy would expand motor function and improve the lives of many disabled people, it resonated within an echo chamber of the

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20th century that presented disability as a lamentable regression of an imagined linearity to humanity’s adaptive evolution.

Thus “battle” talk is not merely a convenient code for the way the telethon presents itself. It is key to the formal and conceptual circuit the program uses to enroll participants and direct them about the urgency and propriety of their work. The characteristic features of the telethon become central to the way the entire cast of participants must work together to “beat” the forbidding, faceless foe that is disease and disability, a process measured in time and donation totals.

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We can now turn to two key props that illuminate the role of endurance in the telethon: the clock and the toteboard. It should come as no surprise that both of these objects are prominently displayed next to each other year after year, and that both are audited by the same accounting firm.


The telethon as a race to support the seemingly automatic good work of the MDA against the unwavering progression of time incorporates the notion that the telethon is also ultimately a battle against disability. As Lewis makes clear, not supporting research
that might cure disability could be facilely excused by an economic downturn or political inefficiency. And yet, the quest to eliminate disability is a project so valorous that it exceeds these constraints – and also represents what Lewis repeatedly claims is the ultimate American act of generosity. The race to raise as much money as possible is fueled by the alleged abjection of disability, a representation of bodily difference that rarely allows for disabled people to be seen as independent and content. Thus while telethon hosts more frequently talk about the race against the clock, they draw on the gravitas of disability as the ultimate opponent. The toteboard and the clock become tools for transforming an abstract battle against the social threats of disability into measurable metrics.¹⁵³

The toteboard and clock also manage the ritual uncertainty that makes the battle suspenseful. As Marvin and Ingle write of the homologies in the rituals of war and elections, “Uncertainty heightens ritual by investing it with consequence.”¹⁵⁴ This, in turn, contrives participants’ ritual faithfulness as a necessary condition for the resolution of group crisis, which in this case is the twinned threat of not raising enough money and not being able to find a cure for muscular dystrophy.

¹⁵³ It is important to note that not all telethons presented disability in the same way. The United Cerebral Palsy Associations regularly included segments that affirmed the independent living of people with disabilities. In one of many similar “mini-docs” that aired on the 1989 UCP telethons, a disabled man who works as a lobbyist for disability legislation talks about the kind of work he does and how he advocates for policy to acknowledge the integrous lives of people with disabilities. “UCP 1989 Mini-Docs,” first broadcast Jan. 14, 1989, United Cerebral Palsy of Middle Tennessee Archives. The Muscular Dystrophy Association was far and away the organization with the strongest vice-grip on the idea that disability is an abject tragedy, owing largely to Jerry Lewis’s unwavering stance that – as he once put it in a Parade magazine feature – someone with MD is “half a person.” Jerry Lewis, “What If I Had Muscular Dystrophy?” Parade, Sept. 2, 1990. While the telethon genre as a whole is often reviled by those in the disability community, we must note that its deepest ableism comes from the race frame that implicitly relies on a naturalized requirement of able-bodiedness and not merely from the contents that fill the ritual frame.

¹⁵⁴ Marvin and Ingle, Blood Sacrifice and the Nation, 250.
The telethon’s battle scripts are key examples in the form of media events that Dayan and Katz typologize. Elucidating the formal features that align and combine with the contest and conquest scripts we can see across many kinds of media events allows us to better understand how it is that telethons synthesized such deep-rooted public feelings about disability, generosity, and autonomy, which, in turn, help us understand how the form remained so highly legible and popular for decades in the latter 20th century.

**Off Script is On Script**

Having outlined the two key scripts of the telethon, this section and the next explore – as a test of the analytic structure being proposed – key features of the telethon. The telethon’s hallmark features, like the use of improvisation, can be understood as part of the centrality of endurance this chapter lays out. Though there were some moments when Jerry Lewis was sweating and panting, especially at the end of his telethons when he used a stool for his final, exhausted conclusions, many telethon performances were marked by something subtler: improvisation. Running off script, haphazard to a point, helped telethon hosts emphasize their programs’ length – and also served to substantiate the authenticity of the endeavor against the largely scripted television landscape. Otherwise precious screen time was drawn out as hosts would sometimes explicitly tell their audiences they had lots of time to fill. During the 1990 MDA broadcast, Lewis fills time by telling a story about his hosting of the 1958 Academy Awards. His producers told him not to prepare extra material, but in the end they ran 41 minutes short.155 This, Lewis suggests, gave him practice for the telethon’s demand to fill time for far longer.156

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155 “MDA Jerry Lewis Labor Day Telethon: 25th Anniversary [Hour 22],” first broadcast September 1, 1990, Paley Center for Media Collection, Catalog ID B:35458.
156 It is interesting to note that in the early years of the telethon, much of television content was live. And thus viewed against other live shows, the telethons often seemed sloppy to a fault. In his dissertation about
generalized aesthetic of improvisation is a hallmark of the telethon form. Jerry Lewis’s comedic styling is most emblematic in this regard. He often used the production itself as fodder for jokes during the time he needed to fill. In the 1992 national broadcast, for example, Lewis routinely walked directly up to the camera, ostensibly to talk with the camera operators he mentions by name, but in so doing made it very difficult for them to get any kind of shot of him. He did this many times to the laughter of the live audience and one time concluded the bit by saying, “A little rehearsal, you know, would help us!”  

This kind of performance helped stress that the broadcasts could only be produced and rehearsed to a point. The extreme length, and the fact that Lewis typically did not take long breaks for naps even in the middle of the night, communicated to audiences that they were seeing a rare instance of uncontrived and authentic performance. Even his gaffes played a part. Prank phone calls and bloopers that happened during telethons are particularly popular videos on YouTube still, and they implicitly emphasize that the telethon is unique in its liveness since its length is so extreme. While making jokes, filling time, and wandering around stage, telethon hosts communicate to audiences that

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the MDA Telethon, Lawrence Londino writes that in its early years the program faced criticism because “virtually all television programming of that period was done live, and people, even critics, did not accept any difference between a telethon production and any other television variety program. Thus, when they were subjected to the sometimes unpredictable occurrences of a telethon production, the audience compared it with the regular scripted shows they were used to.” As television content became increasingly pre-recorded and more highly produced, the telethon began to stand out as a live media event of a piece with other highly-viewed television rituals, such as award shows and the Super Bowl. Londino, “A Descriptive Analysis of the ‘The Jerry Lewis Labor Day Telethon for Muscular Dystrophy,’” 26.  

157 “1992 MDA Telethon,” Paul Longmore Papers, San Francisco State University, Box 140.  

their show is not subject to the ordinary limitations of television time.\footnote{It is worth noting that Jerry Lewis’s comedic styling beyond the telethon often relied on a similar funnyman aesthetic, one that has a different relationship to disability. A 1986 “Person of the Week” feature on \textit{ABC Evening News} noted that Lewis got his start in the entertainment industry playing his “dumb” act with a “rubber face and squeaky voice.” It is clear from watching these early performances that Lewis is relying on a kind of disability drag, exaggerating supposedly humorous portrayals of a person with a mental disability. \textit{ABC Evening News}, “Person of the Week (Jerry Lewis),” first broadcast September 5, 1986 by ABC, Television News Archive, Vanderbilt University, Catalog ID 105229.} The telethon goes on and on.

Improvisation helps us see that the primary framework of the telethon, in Goffman’s terms, is a television entertainment program. But it is keyed as a battle or race. So while we would expect that in battle the warriors wouldn’t waste time in their work, in fact it makes sense that Lewis reverts back to the more literal framework of the entertainment program to relieve himself and at-home participants from what would be an otherwise unsustainable effort. In other words, Lewis must key the telethon as a battle only periodically or risk losing viewers whose experiences are mediated as a Gestalt effort (i.e., giving as sacrifice mirrored in Lewis’s embodied sacrifice). This helps us see how the telethon’s keying is a tentative dynamic, open to contestation (as will be explored below).

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References to the telethon in popular culture confirm that one of the most prominent ways audiences understood the telethon was in terms of its capacity to waste or fill time. While reception data about the telethon can be hard to rely on,\footnote{See discussion of telethon popularity above, pages 4-5.} we can use pop culture references as convenient proxies because they indicate not just that the telethon was popular enough to take up in other media forms, but also the cultural resonances that audiences sensed.
In the years that the MDA production was gaining widespread national popularity in the 1970s, the telethon featured as a plot device in scores of television shows, from a 1975 episode of *Maude*, a 1976 episode of *Welcome Back, Kotter*, and a 1977 made-for-TV movie called *Telethon*. In the decades after, telethon parodies appeared in sketch comedy shows including on *Saturday Night Live* and *MADtv* and an NBC special featuring Richard Pryor. Shows including *Seinfeld*, *Friends*, *Full House*, *Diagnosis Murder*, *Parks and Recreation*, *American Dad* and even *The Muppets* all featured stagings of a telethon. In May of 2015 there was a telethon episode of *Barbie: Life in the Dreamhouse*, an online show whose audience is far too young to have watched the America’s most popular telethons.

That the telethon is such a convenient narrative arc in so many shows is further proof that the telethon relies on its contrivance of uncertainty, out of which emerge a number of options for dramatic tension for writers. Whether Lewis will remain standing

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through the whole broadcast and whether the viewers will send in enough money to reach the goal produce a beginning, middle, and end that fiction often similarly employs. Further, since so many references to the telethon linger on the need to fill or waste time, they also illustrate the resonant features of the ritual by transposing it onto a fictitious analogical scene that exaggerates the telethon’s moral directives.

Consider the series premiere of Steve Allen’s Comedy Hour on CBS in 1967 that concluded with a long segment about the “14th Annual Prickly Heat Telethon.” Allen (appearing as “a man whose name is synonymous with disease: Steve Maudlin”), opens by calling for his viewers to perform ridiculous stunts on account of the telethon’s broadcast like missing work, staying up all night, lifting bail, moving a barge. Allen’s character too starts to weaken and lose his voice. At times he gets mad that the audience hasn’t done its part in helping end the telethon itself. He has hope in the final two minutes of the program that they can reach their goal, but the entire volunteer staff has fallen asleep at the phones. The host announces he’s leaving soon for the next telethon in Chicago, which he suggests is better because it’s for the biggest killer of them all: natural causes.175

At one point near the end of the bit, a tap dancer comes onto stage, dances for three and a half days, and finally collapses. The exaggerated resemblance to Lewis’s tap dancing described above should not be lost: What makes for the laugh track on the show is a relief offered by the parody’s successful pinpointing of the telethon’s contrivance of endurance. As producers of the Prickly Heat Telethon scramble around stage and as the host gangles about with the microphone in hand, viewers are reminded of the not-so-

175 “The Steve Allen Comedy Hour {Series Premiere},” first broadcast June 14, 1967 by CBS, Paley Center for Media Collection, Catalog ID T:29438.
different instances of actual telethons. Lewis’s bowtie – frequently untied but never completely removed – does the work of performing endurance that Allan exaggerates into parody. This sketch is a useful analytic proxy for pinpointing how the telethon’s ritual communication of endurance resonated with America’s viewing public.

**Coursing Toward Prophylaxis**

“[H]ow do we explain the increasing popularity of the Jerry Lewis Telethon? In our view, you don't explain it because it has taken on a totally unique character and has carved out a position in the hearts and minds of the American public which defies the traditional forms of analysis and critique.”

—George Simko, Senior Vice President of Benton & Bowles advertising agency

In this chapter I have focused on the telethon’s fashioning of endurance in order to demonstrate some of the reasons that the format remained such a captivating public drama of the body in the latter half of the twentieth century. As I have suggested throughout, telethon analysis must be oriented to the polysemic, multi-modal, and layered communicative apparatus of the format. I have proposed that endurance is the true wellspring of the telethon’s able-bodied ideal – not simply the representations of disability that activists and scholars have focused on.

While the well-being of the main telethon participants was assumedly secure and their sacrifice assumedly healthy, not everyone’s health was as guaranteed. Those not participating in the telethon were in danger. As discussed earlier, telethons’ insistence that disability might crop up at random in audience homes across the country effectively made the decision to donate of a piece with insurance calculation. “Contributions,” Paul Longmore has noted, “became a type of insurance premium: receiving services as a

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payout on the insurance policy.”\textsuperscript{177} An Easter Seals Telethon emcee declared this plainly in 1995: “You know, supporting Easter Seals is just like buying an insurance policy for yourself or a friend or a family member […] We never know when accident or stroke will pay an unwelcome visit to someone we love.”\textsuperscript{178} Uninsured audience members, telethons seem to say, may wake up tomorrow with a disability in the family, but they can rest assured that the telethon, as the altruistic insurer and caregiver, will help ward against it.

This aspect of the telethon is concretized when thinking of the role of health charity telethons within the landscape of public and private healthcare in the latter half of the century in the U.S. more broadly. Telethons presented themselves as filling the gaps in late-twentieth century health insurance problems. Because of upper limits in the income eligibility for recipients of government insurance, many people with disabilities, especially those in the working poor, made too much money to earn government aid but not enough to fully cover the costs of their disability-related expenses out of pocket. This, in addition to widespread discrimination by insurers, meant that people with disabilities were either less likely to have insurance than nondisabled people (and those with major disabilities were the most likely to depend on government assistance) or they were trapped on government assistance without the real possibility of gainful employment that wouldn’t jeopardize their capacity to pay for their access needs. Between the mid-1970s and the end of the 1990s – the same period during which the telethon reached its height – health insurance coverage provided to working- and middle-class American steadily declined.\textsuperscript{179} When telethons presented their work in helping the U.S. health system, they

\textsuperscript{177} Longmore, \textit{Telethons}, 27.
\textsuperscript{178} Qtd. in \textit{ibid.}, 28.
\textsuperscript{179} \textit{Ibid.}, 42.
implied that their services were nongovernmental (and also nonpolitical) solutions to these problems, especially as public funding cuts in the 1990s jeopardized the viability of government aid.

While the telethon presented itself rather explicitly as a kind of insurance, there is an unarticulated yet important drive toward moral prophylaxis that I argue is the telethon’s ultimate goal — and it is also what ties together the features I have noted throughout this chapter. It is not just that the telethon’s donation battle might vanquish or at least alleviate the hard time of disability once it arrives, but that the endurance to enter the fight itself enacts a warding off of disability that is physical and moral. In 1976, Jerry Lewis frequently referred to the “preventative medicine” of the telethon’s work and a key part of one of his monologues connects the telethon-as-insurance claims to the telethon-as-prophylaxis:

> If you do not believe in preventative medicine, as I do, then believe in nothing more than making a contribution for the sake of those who may be in the position of not helping themselves. If you believe in preventative medicine, then help us do the job that we’re trying to do so that with the will of God – God-willing, I should say – nothing happens to your children and we hope they live very happy and healthy lives and play as normal children should. And run [raising finger and shaking it], most importantly, they run.\(^{180}\)

Lewis often insisted on the importance of the capacity to run, most infamously remembered when he was pressed by ABC’s Chris Wallace in 1992 on his degrading attitude toward disabled people. Lewis responded sharply to the criticism: “They can’t run with me down the hall, can they? In truth, aren’t they given half? Haven’t they been left with half? If there’s a degree of measurement, are they whole?”\(^{181}\) Here we see a return to the “thon” in “telethon”: the supposedly natural goodness of the capacity to run.

\(^{181}\) *Prime Time Live*, “Jerry Lewis Telethon,” first broadcast Sept. 30, 1992 by ABC.
We can thus see the many telethon pleas for audiences to “get up” in order to pledge donations as part of this insistence on an able-bodied ideal. Mickey Rooney in 1976 ended his act on stage with a rather abrasive directive for at-home viewers. “I want you to get off your fannies right now,” he said looking at the camera and pointing his finger, “Get on to the phones and make some money for this great cause.”\footnote{1st hour, Muscular Dystrophy Association, *The Jerry Lewis Telethon*, author’s collection, 1976.} Pledging a donation is offered as absolution from lack of physical activity that television-watching invites and thus donating and “running” by proxy are presented as equally valorous for the “great cause.”

In the kind of mediation that is *enacted* and assisted by what is *said*, the telethon’s herculean effort is imagined as automatically salubrious against the supposed malevolence of disability as an individualized and social threat.

As Paul Longmore has noted, telethons often featured talk distinguishing avaricious “takers” from benevolent “givers,” which drew moral boundaries around participation in the event while leaving disabled people as the supposedly automatically pathetic tertiary class (“objects of the benevolence”) upon which this giver/taker distinction gets made.\footnote{Longmore, *Telethons*, 59-70.} To add to this understanding of the civic and moral work of the telethon, I have argued that endurance is a key performance within the telethon ritual. On-screen participants’ displays of endurance – a baton passed from out-of-breath hosts to the acts that filled the clock’s unsympathetic march through the night – are crucial to the way the physical collective activity is morally transfigured and in turn enacts its concepts of charity, autonomy, and benevolence.
Near the end of telethons, the scripts switch considerably; the battle is almost over. It is worth noting how Jerry Lewis closes the telethon, since it is in his final monologues that he offers the most direct accounts of his work, when he is, like a sacrificial lamb, sweating under the hot stage lights. Reporting on the announcement that the MDA would produce its first telethon without Lewis as a host in 2011, *New York Times* television critic writes about Lewis’s performative finish line moments: “He always made a point of looking exhausted, trying to make viewers wonder if he would make it all the way through the 21½ hours to his quavering, maudlin rendition of ‘You’ll Never Walk Alone.’” What his heavy breath started at the top of the show comes barreling through in the final moments of the broadcast.

The lyrics to this closing song condense a number of important themes from the broadcast, including the repetitious imperative to “walk on, walk on” that captures much of MDA’s insistence on the potential for disability to be redeemed into ability. More to the point here is that this song helps extend the telethon into the future, linking the goodness of stamina as it played out during the broadcast to the hope for a future without muscular dystrophy. In its final moments, the telethon attempts to transcend its own test of time. It is through this song that Lewis promises his “kids” that they’ll never walk alone, that even though the telethon is over, MDA’s support is not. It is this song that proclaims that, in the end, it is not the end. In this way, the particular techniques of time that the telethon uses to imagine itself as a conquest are never far removed from its

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attempts to construct global notions of health and well-being that it casts as proof of its benevolence.

But these moral enactments of ability ideals do not naturally or automatically succeed. Disability advocates have made important critiques of the representations produced by telethons. They have stressed that the telethon may have raised extraordinary amounts of money, but it never offered a whole portrait of disabled life; doing so – presenting disability as relational and natural and not automatically abject – would have hindered the telethon’s very aims. These advocates have made clear that the MDA poster children did not by definition live tragic lives, they were not living examples of the need for American charity, they were not sad and helpless. Many of them were, if not for the persistent ableism the telethon constructed, unexceptional.

As I have already suggested, treating content as separable from its form in this case does not produce a properly powerful form of resistance. It is in part anti-telethon activists’ overlooking of the telethon as an endurance event that allowed the telethon to maintain its popularity and legibility, even during the same period when the disability rights movement was burgeoning in the U.S. But anti-telethon activists did sometimes pierce the frame and I would like to pause on one exemplary intervention in order to throw into relief the larger ritual work I have been describing.

Mike Ervin, who had been one of Jerry’s “kids” when he was younger, organized the group he would call “Jerry’s Orphans,” a name that meant to call out Lewis’s hypocrisy in caring only for disabled subjects (children) while stigmatizing disabled adults effectively “orphaned” by his unreliable fatherhood. In the early 90s, this group protested many MDA telethons by interrupting the local Chicago broadcast, handing out
flyers at and around the telethon venue, and asking volunteers to think critically about their involvement in the event.\textsuperscript{185}

At one event in 1991, Ervin and another protester were able to wheel onto the stage of the broadcast. Just as the announcer is about to introduce the hosts, everyone pauses, confused because they normally associate people in wheelchairs as pity props during the broadcast. The protesters shouted “Stop the telethon now!” and “Piss on pity!” as the hosts and crew scrambled to try to get the protesters off the stage. To fill time, the production staff began playing James Brown’s “I Feel Good,” which became an oddly apt soundtrack underneath the protest chants.\textsuperscript{186}

Fig. 2.6: Jerry’s Orphans interrupt a local broadcast of the MDA Telethon in Chicago. Two activists in wheelchairs are on the stage and behind them are tiers of volunteers working the call center. One of the emcees is on one knee talking to one of the activists, Mike Ervin. Captions read: STOP THE TELETHON NOW!

\textsuperscript{185} While many sources mention the early 1990s as the time of the most visible anti-telethon activism, it is worth noting that examples of public controversy around the telethon’s portrayals of disabled people can be found as early as the mid-1970s from groups like Disabled in Action and the National Federation of the Blind. Terri Schultz, “The Handicapped, A Minority Demanding Its Rights,” \textit{New York Times}, February 15, 1977.

\textsuperscript{186} Footage from protestors is found in \textit{The Kids Are All Right}, directed by Kerry Richardson (2005), http://www.thekidsareallright.org/watch.html.
It is worth pausing to note just what makes this scene so rich, since it illuminates the formal framework as it disrupts it. The protesters did not hold signs when they got on stage, which is key to the resulting confusion. Without the use of written language to instruct on-lookers about their role on stage, the telethon’s overriding script about the presence of people who use wheelchairs prevailed; audiences assumed they were part of the broadcast. It was the activists’ grimaced faces that indicated a disjuncture, as they shouted for the halting of the telethon (in two senses: for it to stop then and there during the disruption, and for it to stop being produced each year). Once the producers registered the problem, their decision to play “I Feel Good” to fill time and hopefully tamp down the activists’ voice is even richer: the activists stormed the stage to say, in a way, what the song proclaims. They did not need the pity or the help that the telethon was trying to garner for them – what they wanted was recognition that disabled people could feel good. And yet the song’s Pollyannaish message is just what the telethon was communicating could come to those who donate to the telethon: it feels good to donate to those who are presented as obviously in need. What makes this scene so interesting is precisely the bungled meanings that emerged from the disabled protesters’ contravention of the telethon’s ritual scripts it developed for disabled people during the broadcasts.

In the last chapter I proposed a template for understanding the kind of social order –thons attempt to produce. What analytical terms help us explain how some telethon participants aver the ritual to be effective while others protest outside and vehemently denounce it as a failure? Since ritual theory is often critiqued for its functionalist bent that assumes rather than specifies how and when rituals produce order, contestation offers a window into more grounded insight. The telethon helps us understand the importance of
the body in ritual communication, including in contestations of ritual efficacy. Telethon protest rejected the agreed-upon rules of conspicuous endurance, refusing to let their on-air time be seamlessly enrolled as part of the show’s management of temporality. What made these protests so potent was not their insistence that the telethon did not accurately represent disability, but their refusal of the performances of endurance that heavily rely on an idea of disability as fundamentally pathetic.

The telethon typically moves on. It cuts from one segment to the next, it moves to station breaks. It keeps going, often compelled by the vigorously physical performances of the hosts like Jerry Lewis. But the disabled protestors refused to let the show go on and instead used their presence as a disruption of the otherwise kinetic televisual display. This defiant rigidity becomes a rejection of the telethon’s overall moral imperative that transforms the moral goodness of endurance into a near-future possibility of an end to disability. And this realization leads us to think about embodied disruption as a potentially scalable protest aesthetic within the enduring –thon frame that I sketch throughout this project. It also allows us to glimpse what I have said is difficult to capture in the latent moral work of the telethon ritual: that endurance is a form of moral prophylaxis that helps the telethon appear legible and benevolent.

We know that in ritual work, not all actors perform the same duties. In the case of the telethon, entertainers’ performances of on-screen endurance hail to audiences’ at-home performances of generosity. This proxy dynamic allows the viewing public to understand donations as moral acts enabling physical acts that are prophylactic in nature. Lewis “running” his show is understood of a piece with the salubrious quality of exercise, which gets keyed into a moral domain by the mediation of the broadcasts into the homes
of the American viewing audience. Telethons became a kind of at-home fitness routine not for the body, but for an American ethical drive. This is what I call the telethon’s *moral prophylaxis*.

Fully illuminating this moral prophylaxis is not complete in this chapter, however. We need to know how this form worked in tandem with a whole weave of marathon events that drew from the same cultural valences and potent social values about exercise, health, and disability.
CHAPTER 3: THE DANCE-ATHON & WALK-ATHON

This chapter examines the legibility and popularity of the dance-athon and walk-athon, two forms with unique but entwined histories. The dance-athon emerges in the latter 20th century in part as a revival of an earlier cultural form from, as it’s typically periodized, the 1920s and 1930s in the U.S. The dance-athon’s popularity is twinned with the rise of the walk-athon, a similarly reliable fundraising tool that encodes emergent notions of civic fitness during the professionalization of U.S. charity fundraising industry.

As in the other chapters in this dissertation, I posit that disability can be understood as a central element of –thons’ attempts to manage collective bodies despite the motivations that can prevent disability from being an explicitly discursive object. Disability is enrolled as key to the stakes and rewards of participation without being made visible as a complex category on its own terms. The dance-athon and walk-athon achieve their communicative work, when they do, through scripts that manage participants’ bodies, thereby doing cultural work about disability often without speaking its name. In this way, -thons become key but undertheorized forms in the ways disability becomes a part of late 20th century public life.

This chapter first lays out a periodization for analysis of the dance- and walk-athon in the 1970s. Then, I consider the 1969 release of the film adaptation of Horace McCoy’s 1935 dance-athon drama They Shoot Horses, Don’t They?, offering a close reading of the presence of disability in the film and the ways in which we can begin to locate incipient public affects about embodied endurance in the -thon form in the 1970s. Then I offer data that suggests how dance and walk-athons developed as new conduits for civic and charity ritualization as they grew in popularity throughout the period. I consider
the influences on the post-1968 college campus climate that found dance- and walk-athons to be a unique antecedent to the tumultuous and more directly “political” work of campus organizing during the Vietnam War and the Civil Rights marches. I condense these developments into a mosaic of features that characterize the waxing popularity of *thons in this period, including the birth of corporate philanthropy, Cold War structures of feeling, a renewed interest in what has been called the “new strenuosity” of the body, and emerging reactions to new forms of media witnessing.

This chapter continues the project’s overall exploration of how *thons route their moral enactments through the body, including the chain of vicarious participation, altruistic physicality, and the role of what I call joyful anguish as a feature of conspicuous endurance I’ve argued is a key component of *thon rituals. That dance-athons and walk-athons are often overlooked as background community activities can in fact tell us a great deal about their cultural and political workings.

I treat the dance-athon and walk-athon together in this chapter for 3 reasons: 1) As noted below, both forms go through a period of stabilization in the same period and their emergence into public discourse as traced by the newspaper and periodical sample set discussed later tracks together. 2) Both forms often involved similar logistical structure, including pledge and sponsorship models of fundraising, national charity organization bureaucracy, and scale of participation. And 3) Both forms demand a constant movement, an important achievement of this project’s working definition of conspicuous endurance that undergirds *thon rituals.

I take several methodological approaches to exploring the dance-athon and walk-athon form. In addition to the reading of the novel and film adaptation of They Shoot
Horses, Don’t They?, this chapter also includes a content analysis of historical newspapers and periodicals from across the 1970s. In reviewing 1,276 mentions of “dance-athon” (and other permutations) and 1,609 mentions of “walk-athon” (and other permutations), I consider the way these forms were reported, discussed, and debated as they took shape. This content analysis offers grounded evidence of the popularity and gives some insight into the meanings participants derived from these events. I look at the number of dance- and walk-athons that were fashioned as charity fundraisers, the number that took place on college campuses, and the number of events related to disability, among other considerations that become part of my analysis. The quantitative data are paired with closer readings of particular sources that help tell the stories of these -thons in the period.

Through my study of the formation of these -thons, I argue that they served to effectively and affectively redirect social threats about disability through a newly convenient form of physical charity fundraising that was unique to the media and cultural influences of the period.

The 1970s

I propose that we can best understand the formation of the dance and walk marathon in the U.S. by looking specifically at the 1970s. Periodizations for analytic purposes tend to require some amount of reduction since the long tendrils of historical agency are rarely neatly bound. Yet I find that the 1970s nonetheless offers a unique frame for this part of the project, for several reasons.

1. Incipient popularity
Perhaps the most important reason to focus on the 1970s is the growing popularity of the forms in this decade. As shown in Figures 1 and 2, mentions of dance-athons and walk-athons increase significantly during the 1970s. (For a fuller discussion of the precise parameters for the publications used in this search, including a consideration of the relationship between textual reports of- and actual marathons, can be found in the content analysis section below).

We should note that in the dance-athon mentions in the 1970s, it appears that the frequencies surge in 1970 and 1971 but then dip in the middle of the decade. The early-decade swell can be attributed to use of “dance marathon” in reviews about *They Shoot Horses, Don’t They?* The mentions of dance marathons as they relate to community events is smoother than the graph suggests.

Between 1960 and 1970, there were only 195 mentions of dance-athons and 359 mentions of walk-athons. Between 1970 and 1980, that number flourishes to 1,555 and 2,164 respectively (increases of 697% and 502%). The extent of this increase confirms that, outweighing any potential errors in the optical character recognition software that the Proquest suite uses to search its historical databases, the 1970s represents a pivotal shift.
Figs. 3.1 & 3.2: Search results for newspapers and periodical mentions of dance-athons and walk-athons, 1960-1990.
For detailed discussion of use of the Proquest historical newspaper and periodicals suite below.
Examining the *development* of the forms is also an important reason why this chapter focuses on the 70s. It is, I posit, the initial influences on the stabilization\(^{187}\) of the form that we can glimpse by looking at the 1970s and thus we can expect that these dynamics are strong indicators of the meanings and cultural layers that remain operative in later periods, including through to the present.

2. The release of *They Shoot Horses, Don’t They?*

Stanley Kubrick’s 1969 film *They Shoot Horses, Don’t They?* is perhaps the most watched and celebrated piece of marathon fiction in the latter 20\(^{th}\) century – and it’s a useful object to read for the way it condenses cultural valences of endurance and anguish against a backdrop of shifting epistemological renderings of the body, namely within the paradigms of eugenics and neoliberalism. The film is also an adaptation of Horace McCoy’s original 1935 novel, therefore pinning the narrative to the two temporal locations where the dance-athon emerges most conspicuously in the 20\(^{th}\) century.

McCoy and Kubrick’s deployment of the dance marathon as a metonym for the Great Depression era was of a piece with many who wanted to understand the affective complexity of American culture in the 20s and 30s – including several prominent French existential writers. But the 1969 film adaptation also coincided with the uptake of the dance-athon and walk-athon within a growing national charity fundraising industry,

\(^{187}\) Here I refer to the forms’ “stabilization” following Trevor Pinch and Wiebe Bijker’s social construction of technological systems. Rather than thinking of stabilization as an ontological judgment, they posit that stabilization consists in the antagonism of several competing social groups. Thus, for example, the stabilization of the bicycle in the late 19\(^{th}\) century was a 19 year-old process of negotiation and renegotiation among various parties. When I speak of “stabilization” of the dance- and walk-athon in this period, then, I mean to foreground the contingency and variance of the form. Trevor Pinch and Wiebe Bijker, “The Social Construction of Facts and Artefacts: Or How the Sociology of Science and the Sociology of Technology Might Benefit Each Other,” in *The Social Construction of Technological Systems: New Directions in the Sociology and History of Technology*, eds. Wiebe Bijker, Thomas Hughes, and Trevor Pinch (Cambridge, Mass.: The MIT Press, 1987), 41.
making it a helpful text to complement the sources divined from the newspaper content analysis. So although the novel and film focus on the dance-athon form specifically, the text becomes useful as an object lesson in some of the hallmark features of the -thon that extend to the walk-athon as well.

3. The new nonprofit sector

The rise of a professional charity fundraising industry in the mid- and late-20th century is documented in a small but lively academic literature. While some historians of philanthropy have argued that volunteerism has long been a defining feature of American political philosophy, others have isolated the late 20th century as a unique period of development for the professionalization of the new industry that George H.W. Bush would famously characterize as “a thousand points of light.” The nongovernmental, private, and fragmented nature of this field bears many of the features of what is often called “neoliberalism” and in the discussion below I consider the particular ways we might understand this hulking and sometimes vaguely deployed term by locating it in the embodied work of the dance- and walk-athon fundraiser.

Historian Peter Dobkin Hall has conceptualized 1959 to 1969 as a “period of confusion and fear” when the government’s increased role in maintaining the public welfare as part of Cold War uncertainties drew out considerable debate about whether private philanthropy was obsolete. Increased Congressional debate and regulatory oversight led to a 1964 memo pondering the formation of “a possible national association of foundations,” which indicates the general affinity for consolidation in the period that

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culminated in the passage of the federal Tax Reform Act of 1969 that “represented the end of the great postwar period of growth for foundations and other exempt entities.”

Hall traces a shift from “philanthropy” to the “nonprofit sector” in the 1970s and 1980s. New economic thinking emerged about a tax-exemption status that could help society understand the work and worthiness of a nonprofit’s work. The nonprofit sector thus developed as a meeting ground for the Left and the Right in what Hall calls the “Third Sector, which offered organizational vehicles through which private values could be translated into public ones without the necessity for compromise and accommodation required by political and governmental processes.”

Bush’s 1988 presidential nomination acceptance speech, when he laid out a vision of nonprofits as “a thousand points of light,” marked the apotheosis of the political maneuvers that brought moral and Christian conservatism into alignment with what had before been a liberal-dominated sector, thus in part delivering the flourishing of the nonprofit world we have come to inherit today.

The early formation of corporate philanthropy becomes an important part of this story in the period. As Samantha King demonstrates in her examination of the rise of breast cancer advocacy beginning in the 1970s, corporations find a new consumer culture of giving that aids their profit-driven bottom dollar, further ensconcing charity work with a dominant market imagination. King finds that organizations designed breast cancer as “a marketable product with which consumers, corporations, and politicians are eager to

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190 Ibid.
associate.”

King’s research builds on a literature that seeks to understand effects of Reagan-era deregulation and market dominance in the 1980s, but it leaves important analysis of the preceding period by the wayside, which further suggests that the 70s are rife for examination that I provide via empirical evidence of the development of the dance- and walk-a-thon.

4. The rise of the running marathon

As was noted in the introductory chapter, the 1970s is also when we see the sharpest increase in participation of marathons of all kinds, from the 10,000% increase in the entrants in the New York City Marathon between 1970 and 1980 to the height of the telethon’s popularity to the birth of the March of Dimes’s influential walk-a-thon. Thus it is not the dance marathon alone that blossoms during this period, indicating that the -thon as a larger cultural technique may have been broadly taken up during this period as a tool for assimilating new affects of the body.

“There is a poverty of spirit today as well as a poverty of body.”
—Stanley Kubrick, 1970

“If masochism is the new American indoor sport, then ‘They Shoot Horses, Don’t They?’ should be a flailing success.”
—Charles Champlin, Los Angeles Times film critic

After serving in Air National Guard during World War II, Horace McCoy picked up odd jobs. He was a newspaper sports editor, a soda jerk, a crime writer. But he had long been focused on a career in Hollywood. When he was hired as a bodyguard for a dance marathon in Santa Monica, he turned his experience into a movie script he called

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Marathon Dancers.\textsuperscript{194} Though it didn’t sell, he later turned the script into a novel and had it published in 1935 with a new name: \textit{They Shoot Horses, Don’t They?}

The title of the novel only comes into focus in the final two pages of the book. The narrator, a dance marathon participant named Robert Syverton, is describing the reason he shot and killed his partner on a pier outside the dance hall. He remembers a summer on his grandfather’s farm in Arkansas when one of the horses had broken her leg while ploughing the fields.

We stood there looking at her, just looking at her. My grandfather came back with the gun he had carried at Chickamauga Ridge. ‘She stepped in a hole,’ he said, patting Nellie’s head. My grandmother turned me around, facing the other way. I started crying. I heard a shot. I still hear that shot.\textsuperscript{195}

Then he recounts the moment his dance partner, Gloria Beatty, gave him a small pistol and asked him to “pinch-hit for God.”\textsuperscript{196} Throughout the novel, Gloria features as an inconsolable and tragic character. She sees no way to achieve her dreams of becoming a movie star, which rankles into an assured impossibility for her as the weeks of the marathon plod along. After two people are shot during the marathon and the promoters decide to shut it down amid rising contempt and moral panic from the surrounding community, the pair goes outside for the first time in weeks. Robert admits Gloria’s depressive effects have tamped his spirit and he begins to agree with her, that she truly was better off dead.

\textsuperscript{194} William Marling, “Horace McCoy,” in \textit{They Shoot Horses, Don’t They?} by Horace McCoy (London: Serpent’s Tail, 1995 [1935]), 125.
\textsuperscript{195} Horace McCoy, \textit{They Shoot Horses, Don’t They?} (London: Serpent’s Tail, 2010 [1935]), 120.
\textsuperscript{196} \textit{Ibid.}, 119.
In the police car after he’s been arrested, a cop asks Robert why he killed her. “She asked me to,” he says. The cop sneers and asks is that’s the only reason he’s got. In the final line of the book he replies, “They shoot horses, don’t they?”

This line would become a famous quip, but not for some time. In its first year, McCoy’s novel sold only 3,000 copies. In the mid-1940s, French existentialist writers such as Jean-Paul Sartre, André Gide, and André Malraux discovered the book and found it to be a fascinating entrée into Depression-era America. Simone de Beauvoir called it “the first existentialist novel to have appeared in America.” But it wasn’t until the 1969 film adaptation of the novel that large American audiences were exposed to McCoy’s work.

The film garnered nine Academy Award Nominations, including Pollack for Best Director, Fonda for Best Actress, Susannah York for Best Supporting Actress, and Gig Young for Best Supporting Actor, which he won. The film earned 6 Golden Globe nominations, including Best Motion Picture, 5 BAFTA nominations, and Fonda’s win for Best Actress from the New York Film Critics Circle Awards. The National Board of Review of Motion Pictures named it the Best Film of 1969.

Reviews and scholarship about the film have focused on the capacity of the dance marathon to allegorize the despair during the period of the novel (the 1930s) and by extension the period of film’s release (the 1960s). “Some sort of parable for the 1970s is hoped for,” Los Angeles Times film critic Charles Champlin wrote of the film, “a kind of

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197 Ibid., 121.
198 Ibid.
199 Marling, “Horace McCoy,” 125.
equation of despair between then and now of Vietnam, ungratifying affluence, intolerance, dangerous additives, and meaningless warranties. Some sort of nonstop self-abrading Mea Culpa is in the works."\(^{201}\) Asked in one interview about the film’s curious success among audiences, Pollack responded, “Perhaps they can see the antecedents of the desperation they now feel packed like a snowball into a dance marathon.”\(^{202}\)

Here, though, I propose another way of reading that addresses the film’s allegorical force and builds from it. Some scholarship has considered the novel in terms of de Beauvoir’s assessment about its early existentialist drive\(^{203}\), yet there has been no critical inquiry into what we can understand as the eugenic sensibility of the novel and thus, the densely coded meanings of disability in the book and in the period. Here I read the novel and film for its treatment and use of disability as a narrative engine, which in turn contextualizes the rise of the dance- and walk-athon as reliable fundraising tools, rehabilitating and revitalizing the eugenic drive into a civic and charity machine.

Agony and existential despair are detailed in Syvertton’s testimony and condensed into the narrative device of the marathon. In the first place, Syvertton and Beatty were literally dancing to survive. The characters meet as two aspiring Hollywood types whose hopes are dampened by the financial crisis. When Gloria mentions a “marathon down at the beach,” Robert balks. “Free food and free bed as long as you last and a thousand dollars if you win,” she says. “The free part of it sounds good,” he replies.\(^{204}\) When she

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\(^{201}\) Champlin, “Depression Dance Craze in ‘Horses.’”

\(^{202}\) Harmetz, “Sydney Didn’t Want to Shoot ‘Horses.’”

\(^{203}\) For example, Lee J. Richmond sets out to show how the novel “anticipates Sartre’s *La Nausée* (1938) and Camus’s *L’Étranger* (1942) as an existential parable.” Lee J. Richmond, “A Time to Mourn and a Time to Dance: Horace McCoy’s *They Shoot Horses, Don’t They?*” *Twentieth Century Literature* 17, no. 2 (Apr. 1971): 91.

\(^{204}\) McCoy, *They Shoot Horses, Don’t They?*, 13.
convinces him to join as her partner, the novel’s core irony falls into place: dancing is not a joyful activity but the means of staying dressed, dry, and fed.

At base, *They Shoot Horses, Don’t They?* is about the equivocal morality of murder. This tension is expressed in part through the dichotomous structure that tacks between the Court’s reading of Syverton’s guilty verdict and Syverton’s own account of the events leading up to the murder. But the words of the court are few, as pithy dividers within the longer narrative from Syverton’s memory. This distinction between the two voices of the novel suggests a kind of flashback in slow-motion as the quick and assuredly guilty verdict in the courtroom of the present interrupts the unspooling of Syverton’s telling. The verdict isn’t all that matters here: behind it might exist a moral defense of Syverton’s actions – that he was, as he says in the book, doing Gloria a “favor” by ending her life. The novel’s structure suggests that this moral complexity escapes the juridical logic that is slowly but surely delivering Robert’s guilty verdict.

Gloria repeatedly quips about her desire to be dead. Peppered throughout the opening of the novel, these moments are camouflaged as part of a colloquialized discourse of suicide, removed from any meaningful reference to death. After meeting an elderly woman who eventually helps earn them a sponsorship, Gloria says, “Christ, I hope I never live to be that old.”205 After assessing their competitors’ seeming capacity for endurance she says, “More and more and more I wish I was dead.”206 McCoy deploys these as idiomatic statements, unremarkable at first.

But they take on new import as the novel’s narrative structure takes shape around Gloria’s impending death. Near the end of their time in the marathon Gloria confesses,

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“The motion picture business is a lousy business […] You have to meet people you don’t want to meet and you have to be nice to people whose guts you hate. I’m glad I’m through with it.” Robert deems this “the most significant thing she ever said” presumably because it indicates her departure from an industry she had, until then, pined after with intense embodied commitment. Being “through with” the business, Robert suggests, was the moment Gloria was “through with” life itself.

In the screenplay, some of these instances are exaggerated to amplify the foreshadowing of Gloria’s fate. (The film’s use of flashforwards suggests trouble, but does not indicate her murder the way the book’s opening admission from Robert’s testimony does.) After she claims cattle are treated better than the dancer, a fellow contestant retorts that cattle get slaughtered. “At least they don’t know what’s coming,” Gloria responds. When discussing her difficulty getting cast in Hollywood, she jokes that the only way to get noticed by an executive is to throw herself in front of his car. Later, when asked what she would do with the winnings, she responds, “rat poison.”

These references to suicide are part of how Gloria features as the irredeemable, depressive figure whose death is a catharsis of the novel’s social milieu. The novel conceals direct references to the larger arena of political affairs unfolding during the Depression era. When Robert opens a door during one of the breaks to look at the sun he hadn’t seen in days, he is chastised for breaching the marathon’s borders. The

207 Ibid., 105.
208 They Shoot Horses, Don’t They?, dir. Stanley Kubrick (1969; ABC Pictures).
characters’ strict enclosure in the marathon is the way the novel concretizes the economic trauma and political disarray of the period.

Robert’s kind-hearted rebuttals to Gloria’s suicide mentions help to ensconce them as opposing forces: Robert as the well-meaning and earnest partner to Gloria as the depressive and incorrigible ballast. They are, for this reason, the marathon’s most striking odd couple. Had Gloria, in the end, ended her own life, her death would have been at a dissatisfying remove from the world of the marathon. Instead, Robert kills Gloria in what we could see as perhaps the only meaningful instance of care in the story. That he acquiesces to her request – without a careful consideration of which of their fingers should be on the trigger – indicates the creep of the disability aesthetic I’m arguing characterizes Gloria’s attachments to others and her surroundings. Though murder is, in the end, the judgment delivered on Robert’s act, the moral tension draws from the possibility that another form of moral logic escapes the juridical one.

In the final catharsis of the narrative, Gloria is depicted as smiling as the bullet tears through her temple. In the parallel of the broken-legged horse shot to death, Robert’s grandfather claims death as “the only way to get her out of her misery.” In the film, Gloria’s character offers another animal analogy not in the book. Recounting the howling of a sick dog from her childhood, she asks, “What the hell good is God doing sitting around up there?” With a wry smile, she tells us taking the dog to a comfortable spot on the couch in the middle of the night. She trails off without finishing what she did. Gloria comes to occupy the role of the dog and the horse in these meta-narratives: a disabled figure whose termination is couched as a morally justified release.

210 McCoy, *They Shoot Horses, Don’t They?*, 120.
In the world outside the film, the 1960s were an important development in what historian of medicine Daniel Kevles would call a “new eugenics” paradigm.\textsuperscript{211} Informed by biochemical genetic research and genetic engineering that innovated earlier forms of eugenic science seeking to eliminate disability from the human population, “new” eugenicists helped form the basis for a social and political platform that was being assembled by philosophers like Peter Singer, who would famously articulate a theory of “practical ethics” in 1979 that deemed abortion, infanticide, and euthanasia to be morally defensible acts when preventing disability.\textsuperscript{212} As historian of anthropology Ann Stoler has argued, eugenics operated as an important technology for fantasies of colonial domination, sexual control, and racial purity.\textsuperscript{213} Though the eugenic paradigm throughout the 20\textsuperscript{th} century would not develop without controversy, we can note nonetheless that both the novel’s release and the film’s release occurred during public deliberation about eugenics and, therefore, about disability.

Against this backdrop, the novel focuses its moral tension on the possibility that Gloria’s murder can in fact be understood as a form of euthanasia. The killing is preceded by a host of other “eliminations” from the competition relating to disability, which preface and foreshadow her more intense and literal elimination. Two contestants experience psychotic breaks, one older contestant dies of a heart attack, and a pregnant contestant is deemed unfit to continue. With the marathon serving as the narrative proxy and ironic space of safety within the Depression era’s cruelty and absurdity, each

\textsuperscript{211} Daniel Kevles, \textit{In the Name of Eugenics: Genetics and the Uses of Human Heredity} (Cambridge, MA: Harvard University Press, 1985), 251-268.
elimination enacts the logic of social Darwinism. To cast the novel’s narrative function even more bluntly: the marathon contest *is* society and elimination is the game’s cardinal conceit.

While each of the eliminated disabled figures is or becomes marked by their disability, Gloria remains in the competition as an *unmarked* disabled figure.214 And because the dance marathon relies on a set of legible rules – if only followed as convincing performance from its actors – the visibility of participants’ deviance is crucial. Taking up the work of disability scholar Ellen Samuels, we can see how the visibility of deviance was key to the world outside the novel, the world the marathon conceit ironizes and focuses. What Samuels calls “fantasies of identification” names the powerful will to believe that embodied social identities can be fixed and verified, despite the tenuous nature of these distinctions.215 Nonapparent disability within these fantasies took on particular significance, leading to the emergence of what Samuels calls “biocertification,” the attempts to authenticate a person’s social identity through biological evidence.216 It comes as little surprise, then, that the novel focuses its moral ambiguity on an invisible or impossibly visualized disabled figure.

Furthering the novel’s moral tension is that Gloria is not cast as congenitally or pathologically depressed. She is *made disabled* by the period’s hopelessness and despair.

214 When I say Gloria is “unmarked” by disability, I am referring to the lack of apparent, permanent indications of disability. Erving Goffman usefully distinguishes between “discredited” actors, such as people who use wheelchairs, and “discreditable” actors who attempt to manage information about stigmatizing identities. Facialy, Gloria may not be understood as a disabled figure, though the story accumulates the ways she can be understood as disabled and heightens her “discreditable” status until the very end. Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York: Penguin Books, 1990 [1963]), 161.


216 McCoy, *They Shoot Horses, Don’t They?*, 122-126.
Though all of the characters by dint of their placement within the metaphorical gauntlet of the dance marathon are affected, Gloria’s sense of despair as an individual character trait resonates more intensely with the wider sense of despair. Throughout the story, she eschews friendships and often antagonizes other contestants with her nihilistic musings. During one of the most visceral and wrenching sequences in the film, a female contestant awakes from a nap into a psychotic break. When one of the marathon organizers shows her a rare amount of compassion – holding her close, fully clothed, in the shower as she settled – Gloria quips that she expected him to charge everyone for his performance of helping her. “No,” he says, sincerely, “it’s too real.”

Thus, her death can be seen as the symbolic embodiment of social ills. Perhaps the most direct connection between the disabled figure of Gloria and the eugenic paradigm I am proposing constitutes the background of the narrative structure is Gloria’s interaction with a fellow contestant who is pregnant. With increasing agitation, the pregnant woman’s husband confronts Robert, warning him to have Gloria stop harassing his wife about getting an abortion. Gloria’s exact reason for advocating for the abortion is usefully ambiguous: because she believes the child will be damaged by the grueling marathon stress on the mother and, perhaps, because she believes children shouldn’t be born into such a harsh world in general. This escalates into a fight when the man strikes Gloria. As the fight is broken up, Gloria gives up the harping and seethes with sarcasm. “I’m through wasting my breath on her,” she says. “If she wants to have a deformed baby, that’s okay by me.”

This scene casts Gloria as an anti-reproductive character, of a piece with the way
disability – here as a social role Gloria inhabits – is figured as atavistic for the humanity
proxied by the novel. Gloria is thus the key figure in what disability scholar Rosemarie
Garland-Thomson would call the aesthetics of “eugenic world-building,” which she
defines as “the ideology and practice of controlling who reproduces, how they reproduce,
and what they reproduce in the interest of shaping the composition of a particular
population.”\(^{218}\) This world-building project, Garland-Thomson argues, involves
separating worthy from unworthy citizens in order to make decisions about who lives and
who dies. The transformation from McCoy’s own experience at a 1930s marathon into
his novel and finally into Kubrick’s film suggest the enduring influence of the eugenic
drive throughout the 20\(^{th}\) century.

As the film is released to critical acclaim, something else is happening to the
marathon form. As noted earlier, running marathons begin to draw more and more
participants and become big-tent events in major cities. Dance-athons and walk-athons,
too, become regular features of community calendars around the U.S. But they’re not
figured as symbolic arenas for the determination of life and death. They become
something more subtle: arenas for the determination of generous and needy citizens.

An article published in The Washington Post shortly after the release of the film
begins to suggest this affective shift. The film “paints a very grim picture of the dance
marathon craze of the 1930s,” writes reporter Gary Arnold. “But the attitudes of writers
and directors conflict with the memories of former marathon dancers.”\(^{219}\) One of the

\(^{218}\) Rosemarie Garland-Thomson, “Eugenic World-Building and Disability: The Strange World of Kazuo
Ishiguro’s Never Let Me Go,” Journal of the Medical Humanities 38: 134.
dancers characterized the time of the dance marathons as one of “great togetherness.” This “togetherness” would become a new way to think of dance- and walk-athons as civic and charity events.

In this section, I report on a content analysis of 1,276 citations of dance-athons and 1,609 mentions of walk-athons over the course of the 1970s. I turn to newspaper and periodical sources to develop an empirically-grounded and close examination of the stabilization of these forms throughout the decade.

**Method**

Throughout this project, I have emphasized that –thons derive their capacity to organize cultural action not through what is *said* during events, but, per our Rappaportian framework, by what bodies *do* during them. I have stressed that this communicative skein is irreducible to speech alone and that the meanings of –thons accrues through the unique forms of ritual communication that also include affect, embodiment, gesture, and collective physical activity.

The difficulty in studying eventful experiences, however, comes from the foreclosure of direct observation of many of the channels of –thons. It is, of course, impossible to take a seat in the gymnasium of a 1975 dance-a-thon, despite how simple it may seem to be able to understand an event through observation. Even contemporaneous observation must reckon with the collective affective layerings involved in organized social action, or what Raymond Williams would call a “structure of feeling.” In his eponymous 1977 essay, he defines structures of feeling as cultural activity of the present. While conventional methodological approaches unwittingly treat activity in the past
tense, since “living presence is always, by definition, retreating.”\(^{220}\) Gaining access to “all that is present and moving, all that escapes or seems to escape from the fixed and the explicit and the known” is what Williams proposes is the more difficult but richer analytic exploration. Although structures of feeling may be “retreating” as we try to capture them with adequate complexity, rituals can be understood as pedagogical tools when otherwise illegible social affects are made tangible and in some sense real. Thus we will do well to treat the dance-athon and walk-athon as domains for collective learning and direct our attention to sources tasked with narrating and reflecting on these pedagogical moments.

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This content analysis used the ProQuest suite of historical newspapers and periodicals to return results on the permutations of the dance- and walk-athon. The results yield 1,276 uses of the terms “dance marathon,” "dance-a-thon," "danceathon," or "dance-athon" and 1,609 uses of the terms “walk marathon,” “walk-a-thon,” “walkathon,” or “walk-athon.”\(^{221}\) Appendix 3A details the full list of databases used for this search as well as the publications that were surveyed.

The majority of the articles studied were newspaper content. The sample included a diverse set of article types: calendar listings, short event announcements, conventional reporting from events, letters to the editor, advertisements, TV guide listings, reviews,

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\(^{221}\) The original results included a slightly wider sample (1,295 and 1,655 respectively), but sources were excluded for erroneous references (errors in the optical character recognition technology), non-U.S. references, or lack of access to source material.
and others. Included in the study were other types of content, like magazine articles and scholarly publications published in the period.

The sources in the sample set used for this study are also varied and thus do more than simply offer journalists’ accounts of marathons. The sources include advertisements, reviews of fiction and dance and film, and opinion essays that form a mosaic of various textual evidence that informs the findings of this chapter.

Though the search method yielded 1,276 uses of some variation of “dance-athon” and 1,609 uses of some variation of “walk-athon” it is important to keep in mind that this does not correlate to the actual number of marathons across the decade. As will be explained below, the collected sources often referred to the same event, reported several times in the same publication or by different publications, which means the number of unique marathons in the sample is much lower than the sample size. The sample assembled using ProQuest’s historical newspaper suite includes a range of publications but generally does not include newspapers from small suburban and rural markets, which tend to be either absent from archival records, not catalogued, or otherwise not searchable. Nonetheless, I argue the sources in these samples overcome these limitations by dint of their volume and because the geographic diversity nonetheless samples from a diverse set, especially since many major U.S. newspapers in the period catalogued and reported on events in surrounding suburban areas.

After the sources were collected into a spreadsheet, I developed coding categories. Because these categories often emerge through the interpretation of the sources and can be difficult to outline before examining the documents, I coded the first 100 sources with a general idea of the categories that would aid the questions guiding this
chapter. Then I reevaluated the categories, shoring up any inconsistencies, and establishing guidelines for each:

**Dance marathon/Walkathon**

One of my main objectives in coding the data was to understand whether the source referred to a specific marathon that occurred within the study’s period or whether it referred to the form in general, a marathon from a different period, or, as was the case in the early years of the period following the release of *They Shoot Horses, Don’t They*, a work of art or fiction that included a dance- or walk-athon.

There were very few instances of unclear codes in this category: 14 dance-athon sources and 22 walk-athon sources. In the handful of cases where, for example, it was not obvious whether a reporter was using a glib colloquialism to refer to an event that the organizers did not label themselves as a dance- or walk-athon, I referred to the original criteria of –thons that I detailed in the first chapter: Was there a discernible temporal extension? Did the event involve collective physical activity? Did the event require conspicuous endurance from participants?

There were 2 categories for sources that did not deal with marathons as outlined here: 1) **Colloquialism**; any use of the dance-/walk-athon as a metaphor, simile, or other semantic proxy for describing another event (such as a review of a boxing match described as a “dance-athon” or a poor pitching performance in baseball resulting in a “walk-athon”). Instances of catachresis – the incorrect use of the phrase – were also coded as “colloquial.” In the walk-athon sample, “colloquial” codes were accompanied by some other specific codes, including “sports analogy,” “dance-athon,” and “strike.” And 2) **Indirect mention**: any use that referred to a marathon (as coded above) outside the
period under investigation or to the form without reference to a specific event. For example, mentions of a horse named “Danceathon” in race results was coded as “indirect mention.”

Disability

A source was coded for disability when it mentioned any kind of disability in relation to a marathon, such as when an event was a charity benefit for an organization that seeks a cure for sickle cell anemia.

In some cases, the boundaries of the term “disability” were difficult to discern. In particular, marathons benefiting the American Cancer Society were a liminal case in this category. It is expected that people with cancer might not readily identify as “disabled.” However, I used the social model of disability to inform the coding for disability, meaning I included all references to sickness, illness, and disability. As disability theorists have argued of the social model, it allows “disability” to be used to name contradistinctions to able-bodiedness that allow us to glimpse the expansive nature of disability to include sickness, illness, and all forms of impairments.²²² It is helpful to note that the Americans with Disabilities Act, enacted in 1990 based on the social model, also takes this view of what “counts” as a protected case. Therefore disability in this study was coded as that which is not able-bodied more than it is a unique category all its own.

It is important to note that most sources coded as disability were not ambiguous. Dance-a-thons for the Muscular Dystrophy Association, Multiple Sclerosis, Sickle Cell

Anemia Foundation, and Easter Seals were dominant in the sample. Walk-athons for the March of Dimes were dominant, explored below.

**Competition & Fundraising**

If a source mentioned prizes or winners of a dance- or walk-athon, it was coded as a competition. Often part of the competitive element was a mechanism for fundraising. If a source mentioned pledges or sponsors from participants or a charity benefitting from monies raised, it was coded as a fundraiser. In the walk-athon sample, sources mentioning a pledge or sponsorship model of fundraising were coded as “pledge/sponsor.” In a smaller category, sources that describe a marathon as promoting a consumer good or service, it was coded as “promotional.”

**College event/school event/youth event/religious event**

Sources that mention events hosted at, by, or in cooperation with colleges or universities were coded as “college event.” Sources with mention of fraternities or sororities’ involvement were coded as “greek life.” Sources hosted at, by, or in cooperation with schools of any kind, including elementary, middle, and high schools were coded as “school event” in the dance-athon set. Sources hosted at, by, or in cooperation with youth organizations were coded as “youth event” (and all school and youth events were coded as “youth event” in the walk-athon sample). Sources hosted at, by, or in cooperation with religious organizations were coded as “religious event.” In the walk-athon sample, events organized in connection with civil rights organizing (mostly those organized by the NAACP and a nationwide campaign to ratify the Equal Rights Amendment) were coded as “civil rights.”

**Fiction**
Sources that mention events as elements of fiction, such as a dance marathon as part of the plot of a sitcom episode, were coded as “fiction.” Any other reference to dance marathons in film or literature were coded as “fiction.” All references to *They Shoot Horses, Don’t They?* were coded in a separate category: “They Shoot Horses.” As a related category, instance of professional dance companies and dance presenters using the phrase “dance marathon” were coded as “professional dance.” In the walk-athon sample, sources citing television, radio, or film representations of walk-athons were coded as “popular culture.”

**Scholarship**

Theses, dissertations, and other academic sources in the time period were coded as “scholarship.”

**Period references**

When a source made explicit reference to a particular period, it was coded according to its decade of reference. For example, a source mentioning the “fad of dance marathons in the 1930s” was coded as “1930s reference.”

In all cases, codes reflect what is included in the textual source and not what may have actually been the case. For example, if one article about a college walk-athon mentioned the fundraising aspect, the source was coded as “fundraising.” If another source about the same event did not mention fundraising but I knew there to be fundraising, I did not code for fundraising in order to preserve loyalty to the textual evidence as it was published.
Dance-athon Results: At a Glance

This analysis included 3,219 unique codes on 1,276 uses of the words “dance marathon,” “dance-a-thon,” “dance-athon,” or “danceathon.” The average number of codes per source was 2.52. The fewest number of codes on a source was 1 and the most was 6.

The most common code in the set was “dance marathon,” indicating a source mentioned an event that happened in the sample period, contra mentions that referred to They Shoot Horses, Don’t They? (n=176), another form of fiction (n=82), colloquial uses of the phrase (n=231), or other mentions that did not refer to actual events organized in the U.S. between 1970 and 1980. The 728 “dance marathon” codes were nonexclusive.
mentions, which means this figure includes sources that referred to the same event. The sources on unique dance marathon mentions are discussed below.

The second most common code was “fundraiser,” with 586 sources citing an event that was raising money for a cause. Unique mentions of fundraising dance marathons are discussed below.

The most frequently cited time period in the sample sources was the 1930s (n=49). Of codes relating to youth-organized marathons, the most frequent code was “college event” (n=250).

Of perhaps more interest are the unique dance marathon mentions; that is, the non-duplicative references to dance marathons between 1970 and 1980. Unique mentions were isolated during the coding process by highlighting only one source in a set if
multiple sources referred to the same event. This smaller sample of 440 sources offers insight about events as they were organized in the formative period of the dance marathon form.

351, or 79.8%, of the 440 marathons cited during the period were fundraising events. 148, or 33.6%, of the marathons were sponsored by, at, or in cooperation with colleges or universities (13 or about 3% being organized by sororities or fraternities). Another 59, or 13.4%, were sponsored by, at, or in cooperation with schools and 49, or 11.1%, were sponsored by, at, or in cooperation with youth organizations. Combining college, school, and youth events, 256, or 58.2%, were organized by young people broadly conceived. 83, or 18.9%, included competitive elements. Fewer marathons included promotional dimensions (i.e., events designed to advertise a commercial entity, generally distinct from fundraising events). And fewer events were organized by religious groups or professional dance organizations.

Perhaps the most important finding from this subsample of the analysis is that 271, or 61.6%, of unique dance marathons mentioned in the source publications between 1970 and 1980 in the U.S. related to some form of disability. This is not merely coincidental, since I’ve been arguing throughout this project that *thons are an especially amenable form for the embodied ideologies of ability. Though not all dance-athons have explicit references to disability, the majority of them in our sample do, which allows us to then examine this proximity in the decade of the form’s key development and popularization.

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223 In selecting the source among multiple entries referring to the same event, the source with the highest number of codes was highlighted. However, sources referring to the same event typically had the same codes.
In the discussion that follows, I pay particular attention to the role of disability within the sample set and suggest connections that help draw out the ways the dance marathon was revived from an earlier trend into a doubly-valenced event form that passed over the existential and metaphorical dread coded by *They Shoot Horses, Don’t They?* and into an occasion for Americans to articulate values of the body through civic and charity activity.

**Walk-athon Results: At a Glance**

This analysis included 5,619 unique codes on 1,609 uses of the words “walk marathon,” “walk-a-thon,” “walkathon,” or “walk-athon.” The average number of codes per source was 3.49. The fewest number of codes on a source was 1 and the most was 7.

![Count of All Codes on Walk-athon Mentions, 1970-1980](image)
The most common code in the set was “walkathon,” indicating a source mentioned an event that happened in the sample period, contra indirect mentions (n=59) or other mentions that did not refer to actual events organized in the U.S. between 1970 and 1980. The 1,506 “walkathon” codes were nonexclusive mentions, which means this figure includes sources that referred to the same event. The sources on unique walk-athon mentions are discussed below.

The second most common code was “fundraiser,” with 1,316 sources citing an event that was raising money for a cause. Unique mentions of fundraising walk-athons are discussed below.

Unique walk-athon mentions are the non-duplicative references to events between 1970 and 1980. Unique mentions were isolated during the coding process by highlighting
only one source in a set if multiple sources referred to the same event. This smaller sample of 627 sources offers insight about events as they were organized in the key period as outline above.

554, or 88.4%, of the 627 mentions cited during the period were fundraising events. 238, or 38%, used a pledge or sponsorship fundraising model. 22, or 3.5%, included competitive elements.

173, or 27.6%, of the marathons were sponsored by, at, or in cooperation with youth organizations, including schools. Only 8, or 1.28%, were sponsored by, at, or in cooperation with colleges or universities, 7 of those being sponsored by fraternities or sororities.

99, or 15.78%, were sponsored by religious organizations.

22, or 3.5%, included promotional elements.

As with the dance-athon results, perhaps the most important finding from sample is that 341, or 53.39%, of unique walk-athons mentioned in the source publications between 1970 and 1980 in the U.S. related to some form of disability. Again, this opens us to the opportunity to then understand the ways that ableist notions of the body writ large find the *thon form to be especially useful in attempts to manage meanings of the body.

In the discussion that follows, I complement these quantitative findings with attention to particular and telling sources within the samples. I pay particular attention to the role of disability and the ways through which dance- and walk-athons became

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224 As noted in the dance-athon sample discussion above, in selecting the source among multiple entries referring to the same event, the source with the highest number of codes was highlighted. However, sources referring to the same event typically had the same codes.
occasions for Americans to enact emergent values of the body through civic and charity activity.

At the dawn of spring in Philadelphia in 1975, Inquirer columnist Bill Curry noted a slew of upcoming charity events. “The annual spring marathon madness has set in with a vengeance this year,” he writes. 75 couples had already signed up for Penn Inter-Fraternity Council’s cystic fibrosis dance marathon set to kick off at the Palestra. And “[t]he granddaddy of the ‘-thons,’ the March of Dimes Walkathon, is expected to attract 30,000 persons to tramp the 20 miles through Fairmount Park from Independence Mall.”

Such is a small snapshot of the dance- and walk-athons that dotted community calendars across the U.S. in the 1970s. Often we can find several kinds of -thons on newspapers’ listings of events on any given weekend during the decade. A 1978 article in The Chicago Tribune notes just how many different formats were popular: “[E]vents range from walk-a-thons, bike-a-thons, and jog-a-thons to skate-a-thons, kiss-a-thons, Monopoly-a-thons, dance-a-thons, teeter-totter-a-thons, and more.” These events, especially the well-organized walk-athons of the period, drew tens of thousands of participants – and sometimes hundreds of thousands. And they raised stunning amounts of money. And they were fun.

A Pittsburgh Post-Gazette article from November 12th, 1979 opens by describing what the dance marathon would sound like from a travel agent describing a package deal: “Weekend getaway! Nonstop disco! Boogie for three days and two nights! All meals and

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gratuities included at $100 per couple. (Mattresses are provided but bring your own sheets.)”

The article reports on a dance-athon at Duquesne University benefitting the Muscular Dystrophy Association – to the tune of $100,000. “It was a good cause,” report David Guo writes, “that would feature phenomenal lack of reason.” The “blisters and bandages, bunions and body odor” combined with other seemingly unreasonable activities: dancers who couldn’t stop shaking even while they were on break to eat, goldfish swallowing contests, and many injuries. Despite it all, the article concludes with a quote from one of the dancers: “This is Duquesne at its best.”

In the following sections I explore how the dance- and walk-athon anchor the conceptual apparatus designed in the introductory chapter for this project as a whole: changing collective dynamics employed the body as a site for negotiating and understanding the intangible social affects that paint, as it were, the canvas of cultural life. Dance-athons and walk-athons, like the other cases in this project, continue to help us see how eventful activity in marathons makes manageable values of the body and produce symbolic distinctions between various kinds of citizens. With a trove of evidence divined from newspapers and periodicals that testify to the development of these marathon forms in the 1970s, we can approach the problem by looking closely at instances when these dynamics are being discussed contemporaneously among its participants.

228 Ibid.
229 Ibid.
Joyful Anguish & Embodied Capital

We proposed at the beginning of this project that one of the defining characteristics of the -thon form is the performance of conspicuous endurance. With our archive of -thon media assembled for this chapter, we have the opportunity to look further into these performance to find, as I argue, an aesthetics of joyful anguish.

When a reporter notes that a dance-athon features “phenomenal lack of reason,” he begins to name the seeming contradiction at the heart of endurance performances. And it begins to offer insight into the particular social temporality that -thons emerge within: a leisure time of community activity often hitched to the social institutions of schooling, government, and care work. It casts as ineffable the particular source of the will to participate in these events.

The dance- and walk-athon endurance feat in fact cathexes in this ineffability. What Robert Merton called the “propaganda-of-the-deed” has the capacity to release its participants from the need to say or explain their work in verbal language. They can show it instead.

Where do we find evidence of this pain-in-pleasure I’m positing is an important part of -thon rituals? We find it not in the written accounts – or only partially, obliquely. We can find it perhaps more reliably in images of enduring bodies at work.

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230 Ibid.
231 Though further research is needed to specify this notion of class-inflected temporality, we know that upper-class relationship to charity were often routed through earlier philanthropic models of galas, balls, and benefit dinners. In a 1978 New York Times article about the state of fundraising, -thons take their place as democratized and inexpensive versions of ballrooms festooned for the rich. Alex Ward, “Fund Raising: Few ‘Givens’ in Taking,” The New York Times, June 28th, 1978.
233 The image captions, we should note, are not insignificant companions to the images, as if the images do all the work on their own. The captions often name relationships between those depicted and constrain audience interpretations.
Duquesne University student Tim Melia is lucky Tracy Grose, a nursing student, was his partner in the weekend muscular distrophy dance marathon on the Bluff. He earned that blister with 44 hours of dancing. The marathon ended last night. It netted a record $26,004. Alpha Phi Delta fraternity collected $4,000 and its dancers, Barry Catley and Pam Klinger, were the winners. Alpha Sigma Tau fraternity finished second with $3,309 and Zeta Tau fraternity took third with $2,325.

Fig. 3.7: *Pittsburgh Post-Gazette*, Nov. 22nd, 1976.
Fig. 3.8: Los Angeles Times, Sept. 4, 1977.

Fig. 3.9 Newsday, Mar. 6th, 1978.
Just couldn't dance all night

Mary Beth Ritchie of Oak Park had given her all and could not be moved by her partner or the referee in the closing hours of a dance-a-thon at the University of Illinois (Champaign) Sunday. The National Association for Retarded Persons was benefited.

Fig. 3.10 Chicago Tribune, Apr. 10th, 1979
Fig. 3.11: The Hartford Courant, March 27\textsuperscript{th}, 1972
Fig. 12: Newsday, Jul. 2nd, 1974

Resting their weary feet yesterday on the lawn at New York's city hall are, from left, Alan Shulman, Michael Kenny and Ken Katz.

Fig. 3.13: Chicago Tribune, Apr. 10th, 1979

WALK-A-THON CASUALTY—Robie Jennings, a March of Dimes Walk/Bike-a-Thon last Sunday, volunteer from Rosacea's West Linnos chapter, Don—Jackie resumed walk with friends, Mary Muller and dages blistered foot of Jackie Blumenthal during Evelyn Simmons, right. The girls live in San Marino.
Born out in many photographs that accompanied the written reports, the joyful anguish of marathon dancers and walkers has a peculiar quality at first glance. While the marathoners may be in agony, they enjoy it. Participants testify to the fun of marathon dancing, at once celebrating a “severe” able-bodiedness that is valorized by marathons’ general refusal and possible redemption of the disabled body while also demonstrating their effect in raising donations through their effortful activity. “God, my feet are killing me,” said a nursing student in Boston during a dance-athon in 1979.234 “My leg’s been acting up a little, and I probably won’t be able to move tomorrow morning” said another participant, “but I love to dance.”235

Part of the pained joy derives from the roles that young people play during these marathon events. Dance- and walk-athons are delivered into the 70s from a legacy of previous charity fundraising events, some even from the same charity organizations. For example, in his article “‘Salk Hops’: Teen Health Activism and the Fight Against Polio, 1955-1960,” Stephen Mawdsley chronicles the way the National Foundation for Infantile Paralysis (later known as the March of Dimes) organized teens into volunteer divisions in the fight against polio. And of course the March of Dimes was one of many private health charities that used the figure of the poster child as a key part of public communication throughout the 20th century, securing a relationship between the cultural figure of the Child and the potential for a charity to eradicate disease and disability. These histories sediment adult imaginations about proper and valorous adolescence.

Changes in the post-1968 college campus climate also help us understand why the-thon and its pleasurable agony may have been attractive to young people. In an early

235 Ibid.
1973 *Newsday* article about the growth of dance marathons on college campuses, reporter John Pascal opens by asking, “Can it be that the quaint Andy Hardy-and-all-the-gang kind of old-fashioned fun is returning to the American college campus?”236 Pascal registers his awe at the events, worrying that the students’ ears might be damaged from the constant drone of acid rock played during the 50 hours of near-nonstop dancing. But his vantage point seems inconsequential, something he notes. The dance marathon, despite what may seem bizarre, found a staying power in the students’ pleasure in endurance. “Besides,” he concludes the article, “nobody shoots horses anymore.”237

A sophomore at the State University at Binghamton named Leslie Epstein wrote an opinion piece published in *The New York Times* in April 1974 in which she marks the a new “mood on campus.” While it’s true, she acknowledges, that a beer blast or dance marathon doesn’t “generate the same feeling of something meaningful being accomplished that a moratorium did,”238 there isn’t an overwhelmingly apathy on college campuses as some would have it. This gentle appraisal of the dance marathon – that maybe it does indeed do something, if not on the order of 1968 political activity – is part of what many cultural critics describe as the muted aftermath of the Vietnam War. British filmmaker Adam Curtis, for example, stresses how quickly Jane Fonda’s wartime activism retreated into concern for the body in her turn to making extremely successful workout videos.239

One article names these developments at work in the design of the walk-athon in the 1970s. “After seeing the civil rights marches, antiwar marches, and antihunger

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237 Ibid.
marches of the 1960s, a March of Dimes vice president tried to combine marching and telethons and came up with a walk-a-thon in Columbus, Ohio.”

Perhaps this helps explain the large banner hanging over a walk-a-thon stage in Chicago in 1975: “We Can Walk It Out,” a play on the popular Beatles song of the previous decade.

A certain turn inward, a new care for the self, is suggested in this history, making the -thon form a conduit between a focus on the body as a site for control and self-discipline while at the same time linking the individual body to a collective civic body.

Thus in the 1970s, we can see how these desires get condensed in the paradigm of civic fitness through the marathon form. Notions of vigor and energy that are encoded into the imaginations of youth and youthfulness find a natural home in charity endurance events, where young people can test their physicality to support the good work of charity fundraising. And fears about bodily damage are thus also tempered by these notions of adolescence, becoming a counter-ballast to the role of disability that is often cast as permanent.

The youthful enduring bodies also carry the charge of producing money through their performances. As mentioned above, the pledge and sponsorship model of fundraising was a popular format for walk-athons in the period, likely far more popular than was reported in the sample when short calendar listings may not have noted the pledge model.

A 1978 article in *The Chicago Tribune* about the “-thon fad” does a good job of explaining a general model of pledging and sponsored donations:

> Most of the marathon-type events, which began in this country in 1970 [sic], use the same format to bring in money. Participants receive “pledge forms,” which they take around their

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neighborhood, school, or office. People pledge to donate a small amount of money for each mile walked, lap swam, hour rocked, or whatever. Charity officials indicate on the pledge form how far the participant went or how long he or she pursued the activity, and that person is responsible for collecting the pledges. A pledge of 5 cents a mile would cost $1.30 for a 26-mile walk. Participation usually costs nothing and donated prizes are sometimes awarded to those with the most pledge [sic] or greatest endurance.242

Another article calls -thons a “physical endurance gambling game” for the way sponsors rely on the performance of their pledge.243 Though it may seem like a gamble to the sponsors who await notice of their debt, participants are nonetheless judged by their endurance. Philadelphia Mayor Frank Rizzo was spotted only completing 2 of the 20 miles in the 1974 March of Dimes walk-athon and was promptly called a “sissy” for not having completed the whole distance.244 -Thon participants (often pre-working youth) generate funds through their effortful endurance and this performance enrolls vicarious participants (often working adults) in a system to produce what is made to appear as a community’s civic capital.

242 Ibid.
244 “People,” Philadelphia Inquirer, Apr. 30th, 1974.
Thousands of children are born each year with birth defects. Many will not live until their first birthday. Every child has the right to be born healthy. You can help make it happen.

SIGN UP NOW
TO WALK IN THE MARCH OF DIMES
WALK-A-THON
SUNDAY, APRIL 28th

20 MILES.....NO PROBLEM

- WALK-A-THON STARTS AND ENDS IN EISENHOWER PARK
- THOUSANDS WILL BE WALKING
- PLENTY OF FUN AND FREE REFRESHMENTS ALONG THE WAY
- AFTERWARDS A ROCK FESTIVAL FOR ALL

REGISTRATION IS EASY
Mail in the completed coupon. You'll receive your sponsor sheet and a Battered Boot Bumper Sticker. Before the WALK-A-THON, sign up friends, neighbors and relatives as sponsors. They'll pledge a donation for every mile you walk. (Sponsor sheet explains the details.)

EVERY WALKER GETS A COUPON FOR A FREE WHOPPER JR.® FROM BURGER KING®

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SEND IN YOUR COMPLETED REGISTRATION FORM TODAY!
Your registration must be received no later than Friday, April 14th.

20 MILES? NO PROBLEM!
NASSAU COUNTY MARCH OF DIMES
366 Jericho Turnpike Mineola, N.Y. 11501

Please send this entry form and entry fee on a check or money order for a $5.00 donation to the Nassau County March of Dimes. All registration forms must be postmarked no later than April 28th, 1974.

Name
Address
City
State
Zip
Telephone

If student, complete the following:
School
Grade
Club or Organization

In consideration of the furtherance of your purpose, objectives and ends, and in consideration of your permitting me to participate in your pledge walk, on behalf of myself, my heirs, Executors, Administrators and assigns, I hereby waive and release you, the directors, officers, employees and agents of the Nassau County March of Dimes and the March of Dimes of America, from any and all liability for damages which I may incur against you, the directors, officers, employees and agents of the Nassau County March of Dimes and the March of Dimes of America, for my actions or inaction, and all injuries which I may suffer while taking part in the walk or to a result thereof.

Signature
Parent or Guardian Signature

PLEASE CHECK: I walked in the 1974 March of Dimes Walk-a-Thon.

Registration Form: 516-741-4445

Fig. 3.15: Newsday, Apr. 4th, 1974.
The capital in sore muscles, as it were, can be understood within the contemporaneous rise of new investments in health during the period. A 1976 *Newsday* article reports on research that finds, as the headline says, “Marathons Healthier in Long Run.” 245 This can be understood as part of what Alan Ingham calls the “national preoccupation with the body” during the period, including the rise of lifestyle politics and running and fitness “booms.” 246 As part of what is often called “neoliberal governmentality,” Samantha King argues, “Individuals were encouraged, rewarded, and penalized for adopting, or failing to adopt, strategies for biological and self-betterment by networks of government that sought to reduce health costs by educating the public against bodily neglect or abuse and by promoting the body as a locus of pleasure, self-expression, and personal fulfillment.” 247 Dance- and walk-athons model civic donation as and through public performances of fitness that were increasingly legible and important forms of social life.

We can thus understand better what reemerges with the rise of the -thon in the 1970s, especially as it relates to the dance marathon, which has an existing literature about its popularity in the earlier part of the 20th century. Carol Martin’s *Dance Marathon: Performing American Culture in the 1920s and 1930s*, 248 and other less historically rigorous treatments such as Frank Calabria’s *Dance of the Sleepwalkers*, 249 consistently use the words “fad” and “trend” to describe the Depression Era marathon.

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247 King, *Pink Ribbon, Inc.*, 49.
This may owe to the fact that dance marathons in the 20s and 30s were *spectacular* events, steeped in the vocabulary of entertainment and designed to produce as much money for the venture as possible (including, in the 30s, the regularity of marathons that were fixed to produce drama with pre-determined winners). But by the 1970s, these marathons can’t simply be understood as “fads” – they ritually enact new values of the body and of capital that would continue to deepen in the remaining decades of the 20th century.

The self-regulation of the body condensed into a -thon’s pledge card might, therefore, be a location to understand the political economic valences of regulations that would arrive in force during the Reagan years. Regulating one’s body in order to produce funds for a seemingly non-political “cause” such as birth defects or cerebral palsy becomes a viable route to helping the collective body self-regulate outside the supposed obvious arena of politics, instead through the growing nonprofit-industrial complex.

The dance marathon develops in the 70s during a key period when disability is emerging as a public category. As the disability rights movement gained traction, formulated its priorities, and began to target various aspects of the ableist world that limited their recognition as full and complete citizens, dance- and walk-athons obliquely assigned value to disabled bodies through the focused gathering they staged as moral trials in the arena of seemingly depoliticized able-nationalism. Dance marathons condense a variety of cultural developments in the 1970s and thus continue to display a central feature this project has been proposing, which is the extent to which *thons externalize otherwise intangible social affect about the meaning of a seemingly threatened able-bodiedness.
CHAPTER 4: THE HACK-ATHON

In David Fincher’s *Social Network*, the film that chronicles Mark Zuckerberg’s founding of Facebook, one scene recreates the company’s first hacking competition. A college student follows a distant noise down a Harvard hallway. It leads him to a room full of rowdy undergrads. As he pushes through the crowd in a dimly lit classroom, we see the action unfolding in the middle of the room: five college kids sitting around a table, intensely focused on their computer screens. Every few seconds, one of them takes a shot of liquor and gets back to work. Zuckerberg walks over to explain what is going on: “They have ten minutes to get root access to a Python web server, expose it as a cell encryption, and then intercept all traffic over its secure port.” If they’re successful, they’ll become Facebook’s first summer interns. At certain intervals, or for every tenth line of code they write, they have to take a shot of alcohol.\(^\text{250}\)

The scene captures the energy of a college sport, complete with clanging cowbells. And though this particular competitive format is more of a sprint than a marathon, it captures the fantasy of intoxication, dedication, competition, and stakes of the hack-athon, when hackers spend a protracted amount of time devoted to coordinating a single project, sometimes for days at a time with minimal sleep.

The depiction of the hack-athon as a rousing spectator sport is a cinematic flair, but in some cases it’s not far off. In September 2015, thousands of college students descended on the Wells Fargo Center in Philadelphia, taking places at their laptops on the floor of the stadium under brightly lit scoreboards. This hack-athon, PennApps, is touted as the world’s largest college hack-athon and it brings a swell of engineering students to

\(^{250}\) *The Social Network*, dir. David Fincher (2010; Culver City, CA: Columbia Pictures).
Philadelphia every year. “Hacking,” said Engineering and Applied Science Dean Vijay Kumar in the opening ceremony in 2015, “is the noblest form of research.”

The past two decades have seen the rise of the hack-athon form. Calling them the “American Idol for programmers,” Wired correspondent Steven Leckert wrote in 2012 that hack-athons have “exploded in popularity” in recent years. “Hackathons, with their come-one-come-all ethos, have emerged as the new forum for networking, learning, and beta-testing new apps and ventures.”

Among the many kinds and foci of hack-athons that occur each year across the globe, those that center on health, medicine, and disability enjoy a perennial share of the attention. In fact, there seems to be a unique aura around the disability hackathon. And the disability community has taken note. “The hackathon is the new telethon,” writes disability scholar Melanie Yergeau.

Is it? In what ways? In this final case in our mosaic of the -thon form in this project, we consider the hack-athon as the most contemporary incarnation of the diffusion of the marathon’s suffix. It is a study of dis/continuity. Though the hack-athon extends some of the ritual dimensions of the enduring body we’ve considered in the previous chapters, the form runs aground on new terrains formed by the importance of code and digital spaces. The role of the physical and collective body, previously analyzed as key to -thon rituals, changes in digital spaces. Thus this last chapter has the unique role of being

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251 Evan Lerner, “Creative Students Get Their Hack on at PennApps,” https://www.upenn.edu/spotlights/creative-students-get-their-hack-pennapps.
meaningfully inconsistent and we begin from the curiosity about the inconsistencies and what they might suggest for the future of the -thon.

I begin by exploring the definitional contours of hacking and the hackathon. The intense popularity and wide uptake of both terms tell us a great deal about the diffusion and lionization of software production as a new kind of labor, a trend historians of computing have been assiduously chronicling in recent decades. I then explore the unique theoretical considerations of the body in hacking. I find that the body has an unsettled and telling role in the constellation of hacker values and aesthetics, which calls us to question the durability of the symbolic enduring body.

Hack-athons, already having difficulty assimilating the body into ritual process, become doubly valenced by a focus on disability, which helps explain the popularity and legibility of the disability hackathon. I then explore these dynamics in the empirical evidence for this chapter: interviews with 10 disability hackathon organizers. I ground my exploration of in an array of interconnecting hack-athons that help us understand what the hack-athon maintains or cannot among the legacy established by the previous chapters.

**What is Hacking?**

In many corners of the popular imagination, hackers are asocial teenage boys who steal credit card information from the safety of their parents’ basements. They are the elusive saboteur *par excellence*. But the term has enjoyed a wider circulation in recent

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years, coming to refer to a much broader set of people. Hackers are radio hams, IT professionals, hardware hobbyists, cyberactivists, and, sometimes, transgressive Internet trolls and criminals.

Steven Levy addresses this problem of definition at the start of his endeavor to document the MIT hacker scene from the 50s to the 80s: “Though some in the field used the term ‘hacker’ as a form of derision, implying that hackers were either nerdy social outcasts or ‘unprofessional’ programmers […], I found them quite different […] They were adventurers, visionaries, risk-takers, artists.”255 Scott Rosenberg, in his book *Dreaming in Code*, defines a hacker as an “obsessive programming tinkerer.”256

Hackers complicate long-standing notions about technology and society. Tim Jordan, for example, maps hacking onto the continual renegotiation between culture and society, concluding that hackers are “the warriors of everyday technological determinism”257 since they unsettle technology’s seemingly monolithic manipulative power over us.

In a similarly expansive way, Gabriella Coleman and Alex Golub have argued that hacking is a “cultural articulation of liberalism.” That is, the fissures and heterogeneity of hacker practice reflect essential fissures in liberalism writ large:

> Because of the ways hackers *so visibly yet also so variably* negotiate, transform and critique a wide ambit of liberal precepts in the context of their everyday cultural world, the practices and ethics of computer hacking afford an exceptional entryway for conceptualizing liberalism as a cultural sensibility with diverse and sometimes conflicting strands.258

256 Rosenberg’s subtitle is another example of the lexical overlap between hacking and religion. Scott Rosenberg, *Dreaming in Code: Two Dozen Programmers, Three Years, 4,732 Bugs, and One Quest for Transcendent Software* (New York: Crown, 2007), 7.
Pekka Himanen also maps hacking onto an historical politics by unpacking the contested but enduring notion of the “hacker ethic” first introduced by Steven Levy in 1984. Himanen, seeing in hacker culture a potential escape from the limitations of the Protestant ethic, identifies seven key values of the hacker ethic: passion, freedom, social worth, openness, activity, caring, and creativity. Accordingly, hackers tend to champion liberal principles such as free speech, transparency, and meritocracy.

In her ethnography of a community of free and open-source software (F/OSS) developers, Gabriella Coleman argues that hacker culture and politics stage important debates about the tenets and limits of liberalism. F/OSS refers to software whose underlying source code is accessible for inspection and editing (unlike proprietary software like the kind that runs Apple technologies). F/OSS includes software that is licensed and monetized but fundamentally nonproprietary and often free (as in freedom, the quip goes, and as in beer).

The valences of “freedom” in F/OSS communities are one entryway into Coleman’s claims that hackers reconfigure the liberal tradition. Their work involves debate about some of the key concerns at the heart of liberal theory, chief among them free speech (Is code speech? If so, when can it be curtailed?) and property rights (How does intellectual property treat property that is designated by its community as collectively authored and owned?). Coleman finds that hackers challenge intellectual property jurisprudence by drawing on ideals of free speech, engaging in a “liberal critique

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of liberalism.”

Hackers,” she writes, “sit simultaneously at the center and margins of the liberal tradition.”

Among the many motivations for producing free and open-source software, Coleman argues hackers are committed to “productive freedom,” a term that designates “the institutions, legal devices, and moral codes that hackers have built in order to autonomously improve on their peers’ work, refine their technical skills, and extend craftlike engineering traditions.” This pursuit of liberal freedom, Coleman says, extends and reworks key liberal ideals such as “access, free speech, transparency, equal opportunity, publicity, and meritocracy.”

Yet many hackers strongly believe that there cannot be a politics of hacking, since tinkering is motivated by a ground-level imperative to figure out how technologies work. This line of thinking has been focused on proving that the rebel does not necessarily have a cause. One hacker, going by the name of Dave, said of the hacker ethic in 1990: “Bah. Too academic. Hackers hack. Not because they want to. Not for any higher purpose. Hacking is not dead and won’t be as long as teenagers get their hands on the tools. There is a hacker born every minute.”

Though hackers themselves may eschew what they see as intellectual bloviating about the definition of hacking, this expansive turn in the signification of “hacking” signals a wider cultural diffusion of the term. Perhaps the broadest definition of hacking comes from philosopher McKensie Wark, whose definition sounds like something a
technology company CEO might say: “Hackers create the possibility of new things entering the world.”265 He later says that while “the terms hacking and hacker emerge [from] electrical engineering and computing,” we can still consider hacking as a “broader awareness of the creative production of abstraction.”266

Hacking is now a legible way to describe a range of activities in various arenas. Arguing that free software has become used by “multiple publics,” Gabriella Coleman writes that “[w]hat was once an odd, exceptional, and subcultural practice has acquired a more authoritative position.”267 There is a longer history to these developments, including the rise of what Jan van Dijk and Manuel Castells called “the network society” in the 1990s.268 The metaphors of computing – and the idea of programmability – become legible ways of explaining and understanding the social world.269

As science and technology scholar Lee Vinsel argues, this expansion can be seen in the explosion of interest in the term “innovation.” Its meteoric rise in usage between the 1960s and 1980s, Vinsel argues, betrays a generalized exaltation of pioneer histories at the expense of a broader understanding of maintenance and sustainability in the discourses about technology and society.270

266 Ibid., paragraph 071.
Hackers have long bemoaned these developments, as much evidence of boundary work as it is a check on the uncritical diffusion of conceptual metaphors about computing. The staff of *Phrack*, a long-running hacker e-zine, used the introduction of their 68th issue in April 2014 to address the supposed waning of the hacker spaces that gave rise to this enlarged notion of hacking:

> We've heard from many corners that 'the Underground' is dead. We'd love to hear those people describe what the Underground is, then. Sure, things change, evolve. Laws, computing power, money invested, political links, technology, every piece moves fast and reshapes the landscape. But if you're reading these lines today, *if you've just finished a 36-hour coding, hacking marathon*, you're keeping it alive.

So thank you, for that.\(^{271}\)

We find it curious that here, the “36-hour coding, hacking marathon” becomes the primordial site of a supposedly authentic hacker culture, a testament to the engrossed dedication to the craft that can make distinctions as hacking gets taken up in more social arenas. Thus we can turn to thinking about the hack-athon form specifically.

What is the Hack-athon?

The first hack-athon is claimed by the community of hackers of OpenBSD, an operating system derived from a research unit at the University of California, Berkeley. The event, held in Calgary, happened in June 1999. “In the months leading up to this, either Theo or Niels Provos had coined this new word ‘hackathon,’” claims a brief history of the hackathon on the OpenBSD site. The event continues to be commemorated by an accidental scrape left in the hardwood floor of the house where the hack-athon took place.

But the *Oxford English Dictionary* dates the term differently. In a Usenet group from 1990 for the fan base of a 1977 short story collection called *Callahan’s Crosstime Saloon*, one user begins a story posted to the list by placing it “just after the Hack-A-Thon,” though the referent is unexplained.

In September 1997, the *Electronic Engineering Times* published an article called “The Rise of the Underground Engineer” about the growing community of “loosely allied” hackers that looked and spoke like “a 1960s radical.” The article describes a “hackathon” of the Windows NT operating system following one hacker’s publication of a 20,000-word technical treatise about the system’s vulnerabilities. This usage of the portmanteau in fact does not conform to the *OED*’s own definition of the hack-athon as “a collaborative computer-programming event,” which is how many hackers understand the term today.

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A more thoroughgoing analysis is needed to understand the early development of the term as it came to name a particular event structure. Some claim that the hack-athon is a largely collegiate affair, one that has widened into other levels of schooling and into workplaces.\textsuperscript{275} Materials for a workshop at the ACM Conference on Computer Supported Co-Operative Work and Social Computer in 2017 states “collegiate hackathons alone attracted over 54,000 participants across 150 events” in 2015, without explanation of the data.\textsuperscript{276} A \textit{Wired} article cites over 200 hack-athons in the U.S. on and off college campuses in 2012, but also without any attendant data.\textsuperscript{277} Reliable data about hack-athons share methodological limitations with other -thons, namely that hack-athons may be produced by small groups without press coverage that researchers might use to quantify the form’s popularity.

But as we’ll explore below, the hack-athon doesn’t remain the same in all places; it is not easily crystallized as a standard form, even less so in recent years. While this variance itself is revealing for the way that hack-athons propagate in various locations, we can begin to get some command of its recurrent features by looking at an array of sources that have attempted to define it.

“A collaborative computer-programming event, typically lasting several days and involving computer programmers, software developers, hackers, etc.”\textsuperscript{278}

“A design sprint-like event in which computer programmers and others involved in software development, including graphic designers, interface designers, project managers, and others, often including subject-matter-experts, collaborate intensively on software projects.”\textsuperscript{279}

\textsuperscript{275} Neil Giacobbi, phone call with author, Aug. 9\textsuperscript{th}, 2017.
\textsuperscript{276} “Overview,” https://hackathon-workshop.github.io/.
\textsuperscript{277} Leckert, “The Hackathon is On,” \textit{Wired}, Feb. 17\textsuperscript{th}, 2012.
“Rapid design and development events at which volunteer participants come together to conceptualize, prototype, and make (mostly digital) products and services.”

“An event focused on computer hacking, and often on tightening up a particular piece of open-source software.”

“A 24-48 hour event where people gather to solve a specific problem with like-minded individuals.”

“Having company employees come in and work all night under the guise of innovation and opportunity with little or not [sic] reward to ones self [sic] for the sole purpose of benefiting the company.”

These definitions tend to cohere around several elements: collaboration, temporal extension, and project focus. In many cases, these features are tethered together by competition and the prospect of a major prize, often sponsored by a corporation with the capacity to select and support young hackers, programmers, or designers.

As with the term “hacking” generally, the hackathon has seen a swell of popularity in recent years, cropping up in places like the White House and the Vatican. Science and technology scholar Lily Irani argues that the spread of hackathons “out of open-source software production into corporate and nonprofit worlds is symptomatic of the promise of entrepreneurialism at work.” The hackathon, Irani argues, helps fashion more and more labor practices after software production.

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Indeed a good amount of the existing literature on hack-athons focuses on the ways that industries determine the kind of work that is done during these events. In their recent study of seven hack-athons in New York City, sociologists Sharon Zukin and Maz Papadantonakis find that these conditions paved the way for sponsors to co-opt the hackathon ritual to “reflect the appeal of Silicon Valley, reshape unpaid and precarious work as an extraordinary opportunity, a ritual of ecstatic labor, and a collective imaginary for fictional expectations of innovation that benefits all, a powerful strategy for manufacturing workers’ consent in the ‘new’ economy.”

Many hack-athons sponsored by tech giants require participants to share their intellectual property rights of any designs produced during the event, with the elusive promise of launching a young hacker’s career.

As we saw in hackers’ response to the expanding use of the term “hacking” in general, hackers also take issue with the diffusion of the hack-athon form into more and more places. In his article “Selling Out and the Death of Hacker Culture,” Rodney Folz uses the spread of the hack-athon as a key indication of the threat to hacker culture:

Today’s organizers have become cogs in a corporate machine. Student hackathons themselves have become corporate. Contractual obligations spell out the mutually agreed-upon worth of individual attendees. Applications and interviews reign supreme (there are even blog posts on how to ace an organizer interview). Hackathons lead dual lives as #brands that speak with the voice of some faceless organization. Major League Hacking, the self-proclaimed official student hackathon league, reserves the right to expel anyone it thinks might upset its corporate contracts.

In conversations about hacker culture and the contested “hacker ethic” discussed above, the hack-athon form is sometimes called to the fore as an object lesson for larger

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dynamics. But what hackers and hacker literature have yet to produce is a thoroughgoing investigation of the role of the body, something our project has centered in the theoretical apparatus that helps make sense of the ritualization of able-bodiedness in many kinds of *thons. Thus before we turn to the empirical evidence in this chapter, we must first inquire about the role of the body in hacking to understand how embodiment might have a new and unique role in digital space and culture.

**The Body & the Hack**

The intersection of disability and technology has a rich literature within the field of disability studies. Aimi Hamraie, for example, traces the epistemologies underpinning the rise of universal design, a paradigm now often touted as disability-neutral for its insistence that everyone benefits from an accessible environment, through the intricacies of “knowing-making” among architectural inhabitants and experts, and technical users and producers. Disability scholar Tanya Titchkosky has usefully theorized access as central to the social meanings of technology and the built environment. What disability studies lacks, however, is a sustained treatment of the role of disability in the digital environment, something that has emerged in starts within the literature about hacking.

Tom Boellstorff’s ethnography of Second Life, an online virtual world launched in 2003, is often a touchstone in discussions about embodiment and virtuality. He contends that a strong distinction between virtual and physical worlds fails to account for the ways that the cultural imagination of physical possibilities have always been central to our experience of the “actual” world. Thus, cultural production in Second Life

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provides “humans with radically new ways to understand their lives as beings of culture as well as physical embodiment.”

Aversion to the strict dichotomy between physical and online embodiment dates further back, perhaps most memorably articulated in the “online disembodiment theory” in John Campbell’s study of gay bear culture on Internet Relay Chat. “This thesis rests on the notion that there is an absolute demarcation between the real and virtual, and therefore a radical disjuncture between experiences in cyberspace and those in the physical world.” Campbell seeks to show how new and no less complex relationships to the physical body can be developed through online interaction. In so doing, he asserts that the body cannot melt into the air in digital spaces: “When we look more critically at what people actually do in cyberspace, we see that race, gender, sexuality, class, age, ethnicity, religion, and looks continue to be differences that make a difference in online social relations.” While Campbell and Boellstorff were far from putting to bed some of the most trenchant questions about embodiment in online environments, they help us understand some of the early ways that scholars attempted to make sense of tendencies to see the body as dislodged or disappearing online.

Hackathons, however, activate another set of questions about embodiment: they are physical, in-person gatherings of bodies collectively working on the production of technical solutions. The most sustained treatment of the kind of activity that interests

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291 Ibid.
292 In many hackathons, we could go further to say that they are gatherings of bodies that are collectively working on projects that are not about the body (i.e., the work is in the code). This opens us to the fascinating distinctions between “hacking” and “making” – borders we won’t treat in detail here except to note that “hacking” tends to refer to the production of code/software or complex hardware solutions.
us in this chapter is Gabriella Coleman’s ethnographic study of hacker conferences, which, she writes, examines “how face-to-face interactions work in concert with digital interactivity to constitute social worlds.”

Coleman first disputes the notion that hacking has displaced physical interaction – or that hackers are only serious hackers online. Then she argues that the hacker conference allows for hackers to distill key features of their “technological lifeworld” in “festive interactivity.”

Coleman places a premium on the role of bodies at these conferences. “[H]ackers collectively condense their lifeworld in an environment where bodies, celebration, food, and drink exist in excess,” allowing hackers who may interact prosaically online to experience physical contiguity as a “high-pitched point.” Though she doesn’t spell out the centrality of the body in any explicit way in her argument for the hacker conference’s ritual status, we can divine it nonetheless.

For example, Coleman argues that after the “copious eating and drinking, maybe dancing, hacking, gaming, sight-seeing, and non-stop talking,” hackers’ bodies are left “worn, torn, and, often, entirely devitalized” – something that may not seem pleasurable to those who don’t pine for what is a quintessential hacker vacation. But this depletion, Coleman argues, comes to revitalize the hacking spirit in the long run. “[A]ny doubts about one’s real connection to virtual projects and relationships are replaced by an

whereas “making” often refers to more accessible problem solving with materials and processes easier to use by non-technical experts. Hence we often see “making” framed in terms of education or diversity and equity while “hacking” is the term preferred by long-standing communities of technical experts. For more on “making,” see Debora Lui, “Situating the ‘Maker Movement’: Tracing the Implementation of an Educational Trend within Public Libraries,” (dissertation, University of Pennsylvania, 2016), 47-55.

294 Ibid., 102.
295 Ibid.
296 Ibid., 105-106.
invigorated faith and commitment to this world.” It is, then, what Rappaport would posit as the non-falsifiable bodily presence in this hacker ritual that secures the temporally delayed feeling of group attachment.

These embodied dynamics of hacking might help us understand the unique forms of pleasure that hacking can produce, in and out of the unique time and place of something like a hacker conference. Technology journalist Julian Dibbell captures the experience of computer work well when he writes that it consists of “endlessly repeatable collusion of freedom and determinism—the warp and woof of fixed rules and free play, of running code and variable input.” These dynamics within the constraints of code production – the “relentless formalism,” as programmer Ellen Ullman says – set the stage for the frustration and the pleasure of hacking.

Hacker pleasure can be a vigorously physical phenomenon, something that pushes at the boundaries of what we consider pleasure. Schematizing the life cycle of a hacker, one dictionary of hacker jargon defines the “larval stage” by what ritual theorist Victor Turner, drawing on the work of Arnold van Gennep, would call the liminal quality of initiation rites:

[A] period of monomaniacal concentration on coding apparently passed through by all fledgling hackers. Common symptoms include the perpetration of more than one 36-hour hacking run in a given week; neglect of all other activities including usual basics like food, sleep, and personal hygiene; and a chronic case of advanced bleary-eye. Can last from 6 months to 2 years, the apparent median being around 18 months. A few so afflicted never resume a more ‘normal’ life, but the ordeal seems to be necessary to produce really wizardly (as opposed to merely competent) programmers.

297 Ibid., 106.
The patchwork affect of frustration and pride is what Coleman argues constitutes hacker pleasure, including hackers’ affinity for humor and cleverness in code and culture. So while Coleman notices that hacking forms a distinct register of selfhood in order to articulate and contest liberal ideals (“an autonomous being guided by and committed to rational thought, critical reflection, skills, and capacity”302), she also notes that the purest form of hacker pleasure transcends the autonomous liberal self:

Because hackers often submit their will and being to technology—and are famous for denying their bodies sleep, at least for short periods—the joy that hackers derive from attending to and carefully sculpting technologies are at times experienced as transcendent bliss. In these moments, utility is exceeded. The self can at once express its most inner being and collapse within the objects of its creation.303

Coleman’s argument about hackers’ tarrying with the tenets of liberalism suggests at many points that hacker culture is deeply invested in the status of the body. But even her argument about the craft and craftiness of hacking falls short of a theory of the body in hacking that forms the bridge to the central questions about endurance in the hackathon form that this chapter investigates.304

The narrow existing literature on hackathons makes little meaningful mention of the body as a component. Lily Irani, writing about the transnational flows of discourses about software and technology production, argues that hackathons are usefully understood in terms of the notions of citizenship they produce. “Hackathons sometimes produce technologies, and they always, however, produce subjects,” she writes.305 Not only does her analysis assume the hackathons are improbably potent and invariant

302 Coleman, Coding Freedom, 11.
303 Ibid., 13.
304 It may be that in some hackathons, the finished products of the event may be understood as evidence of collective material participation and therefore may, in some instances, index an embodied ritual experience. We note, however, that this is a tenuous way to approach the role of the body in the hackathon.
events, a functionalist fallacy, but she subsumes the body under the unspecified category of subjecthood when, I argue, the role of the body is far more complicated in the hackathon form.

In their ethnographic study of issue-oriented hackathons in the U.S. in 2012 and 2013, Thomas James Lodato and Carl DiSalvo similarly assume the body to be a silent partner in the work these events can do. Like Irani, they argue that what is important is not the particular product or prototype designed during the hackathon, but how participants collaborate articulating issues, problems, and solutions. They argue that hackathons produce “material participation,” in one form by producing props for their objects, services, and systems designed during the event, and in another form by constituting what they call “proto-publics” through the ad-hoc collectives that negotiate the boundaries of an issue at play. This notion of “material participation,” however, leaves out the body of the hacker as an element of the materiality and participation at work.

The danger in not seriously considering the embodied dimensions of hacking and the hackathon form is that we end up with no durable framework for differentiating among a cluttered field of hacker activity. Hackathons may indeed produce transformative experiences for some participants at some gatherings. But how can we know if the form itself can be understood in properly ritual terms? Without an analytic frame, researchers tend to assume that all hacker events become equally meaningful when, as we’ll see, many contemporary -thons do not produce salient, meaningful, or useful cases. Instead of seeing this as a conceptual failure, here we study it for the way it
might signal the limits of the -thon form and new developments for the -thon in a digital era.

To do this, we return to the role of the body. Perhaps the most important treatment of the role of the body in hacking comes from communication scholar Douglas Thomas in his article “Hacking the Body: Code, Performance, and Corporeality.” Thomas seeks to locate technology as a process that generates meaning through negotiations with two conceptual poles: code and performance. While code regulates and thus shares a normative function with law and other structuring devices, performance can be understood as seeking transgression, since its capacity is to produce that which cannot be repeated. With some necessary analytic reduction, Thomas holds these as two opposing poles: “The goal of code is infinite repetition without difference, while the goal of performance is the production of an irreducible, unrepeatable event – a singularity.”

But of course neither is legible without the other. To be useful, code acquires a certain eventfulness about it and performance must engage in repetition to be understood. And therein lies the kind of complexity Thomas seeks from decentering rigid binaries when we write about technology.

Thomas argues that hackers demonstrate how the body sits at the limit of code. “In its most general sense,” he writes, “code regulates and defines not by attaching itself to particular bodies, but by abstracting notions that appear to apply to all bodies.” Thus any particular, incarnate “coded body” cannot exist without disrupting the very notion of code. For example, when certain bodies, like those of mechanics or massage therapists

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307 Ibid., 654.
with occupational wear on their fingerprints, “fail to enroll” in biometric systems, it is because the system sought – and could only seek – to apply to all bodies (without, of course, considering that the fingerprint is a necessary condition of code that would disrupt the universal applicability of the code).\(^308\)

But performance, on the other hand, “is the body” and thus challenges the abstract category of code that it is defined against.\(^309\) Thomas then locates the body in hacking within these competing imperatives. For example, he considers how the goals of secure encryption are to empty the code of any reliance on any specific body and yet encryption is routinely threatened by the transgressive performance of bodies in violation. “The performative act of transforming codes into bodies (and also bodies into code) potentially disrupts the entire system of regulation and normativity that allows code itself to function,” he writes.\(^310\)

These dynamics can be understood as new development in the relationship between the body and the text theorized by communication scholar Carolyn Marvin. In “The Body of the Text: Literacy’s Corporeal Constant,” Marvin argues that in systems of literate control, “the suppression of the body constitutes the condition and prerequisite for literate achievement.”\(^311\) Well-crafted text is distinguished by its erasure of evidence of the toiling body that produced it. Thus it is no surprise that medical practice, Marvin shows, has succeeded in its professionalization and quest for cultural authority by literally and figuratively making texts of the bodies it seeks to make claims about.

\(^309\) Italics in original. *Ibid*.
\(^310\) *Ibid*., 660.
Building from these insights about forms of textual control, Thomas articulates a new and important consideration of the body that cannot simply rely on the corporeal dimensions of ritual, as we have been doing in the project and we’ve followed in the intellectual lineage of Roy Rappaport. When hackers write code, they produce a system that attempts to abstract from any given body (the normative function), while relying on its performative interruptions (at a minimum for assessment). In other words, the body becomes a different kind of metric in rituals in and around code, like the hack-athon.

But how do we know? Given that no definitive study or history of the hack-athon has yet been produced, this chapter seeks out interviews with hack-athon organizers in order to furnish some empirical data about the form in general before moving to consider these theoretical question as they manifest in this last study of the proximity between disability and the -thon legacy.

In the following section of this chapter, I synthesize findings from interview data with disability hack-athon organizers. I present these findings in part to add to our understanding of the form generally, including, crucially, reporting on how my interviewees defined the essential characteristics of the form. But I also drawn on these data in order to nuance and extend the theoretical apparatus above, thinking specifically about the role of disability and endurance in the hack-athon.

Table 4.1: Interview Sample At a Glance

<table>
<thead>
<tr>
<th>Event Name</th>
<th>Location</th>
<th>Date &amp; Time</th>
<th>Host Organization</th>
<th>Interviewee</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATHack</td>
<td>Cambridge, MA</td>
<td>Early March, annually</td>
<td>MIT</td>
<td>Jaya Narain, Co-Founder &amp; Co-Director</td>
</tr>
<tr>
<td>Pre-hackathon dinner &amp; one-day event, 8:30am-7:30pm</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td></td>
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</tbody>
</table>

“A multidisciplinary hackathon to help people with disabilities. The goal of ATHack is to bring awareness to the important field of developing assistive technologies. We pair teams of students with clients in the Boston/Cambridge community who live with a disability. Each client has a problem in mind which they face because of their disability. Over the course of the hackathon, students brainstorm, design, and create prototype solutions for their client.”

<table>
<thead>
<tr>
<th>AT&amp;T NYU Connect Ability Challenge</th>
<th>New York, NY</th>
<th>Spring-Summer 2015 Submission period between April and June, judging and public voting in July</th>
<th>AT&amp;T, NYU</th>
<th>Neil Giacobbi, Campaign Manager</th>
</tr>
</thead>
</table>

“The AT&T NYU Connect Ability Challenge is a three-month global software development competition leveraging mobile and wireless technologies to improve the lives of people living with disabilities.”

“In honor of the 25th anniversary of the Americans with Disabilities Act, NYU’s ABILITY Lab is hosting a hackathon focused on digital and wearable solutions for accessibility. Participants will receive the technology challenge Saturday morning. Over the course of the weekend you will meet four individuals with disabilities to discuss some of the issues they face day to day. Interdisciplinary teams will form to build functioning prototypes to be judged by an expert panel.”

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<table>
<thead>
<tr>
<th>Event</th>
<th>Location</th>
<th>Details</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>CajunCodeFest</td>
<td>Lafayette, LA</td>
<td>April, annually Friday 1:00pm – Saturday, 12:00pm</td>
<td>Andrea Aloisio Frey, External Affairs Manager</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Center for Business &amp; Information Technologies at the Informatics Research Institute, University of Louisiana at Lafayette</td>
<td></td>
</tr>
</tbody>
</table>
| “The annual CajunCodeFest Summit and Challenge focus on a new healthcare theme each year. The summit is open to the public and the challenge is open to all students and professionals with an innovative spirit. Teams use data to build apps and tools addressing the [the annual theme] to win cash, prizes and bragging rights.” | 315  

| “Cure It!”            | Cambridge, MA | September-February annually Submission in October, finalist materials in January, winners announced in February | Stephanie Couch, Executive Director; Janell Ciemiecki, Awards Program Administrator; Stephanie Martinovich, Communications Manager; Kayley Brown, Program Assistant |
| Lemelson-MIT Student Prize |               | Lemelson Foundation & MIT                                              |                                  |
|                       |               | “The Lemelson-MIT Student Prize honors promising collegiate inventors around the country. The Student Prize is open to teams of undergraduate students and individual graduate students who have inventions in categories that represent significant sectors of the economy: healthcare, transportation and mobility, food/water and agriculture, and consumer devices.” | 316  

| evoHaX                | Philadelphia, PA | April, 2017 Opening evening panel discussion, day one 10:00am-10:00pm, final day 10:00am-6:00pm | Ather Sharif, Founder |
|                       |                | evoHaX Labs                                                           |                                  |

“evoHaX is [a] series of Hackathons focused on developing accessible technologies. [...] Teams from schools, local tech firms as well as individual participants are welcome to participate. The event will also target a broader range of disabilities through collaboration between professional developers, students, medical professionals, and people with disabilities.”


““The Google Impact Challenge: Disabilities aims to make the world more accessible for the 1 billion people living with disabilities. We pledged $20M in grants to 29 nonprofits using technology to take on a wide range of accessibility challenges.”[^318]

| Hack4Access | Philadelphia, PA | May 30th – June 1st, 2015 Opening happy hour, day one 10:00am-5pm, day two 10:00am-4:00pm | PA Link | Faith Haeussler, Coordinator of Link to Aging and Disability Resources |

“#hack4access will focus on aging and disability issues. [...] There will be plenty of open data to hack, we'll focus our efforts and winning projects on issues impacting older adults and people with disabilities.”[^319]

| MIT Hacking Medicine | Cambridge, MA | April, annually Friday evening 7:30pm-11:00pm, Saturday 9:00am-11:00pm (with late-night hacking space) | MIT | Shriya Srinivasan, Co-Director |

[^317]: The staff member declined to speak on the phone and asked not to be quoted, but answered questions via email, which will be cited accordingly.


“Our hackathons bring together people members spanning the whole healthcare ecosystem. Our teams usually consist of patients, nurses, doctors, engineers, developers, designers, business people, insurance, and policy experts. Together they attack healthcare challenges using a diverse and interdisciplinary approach.”

<table>
<thead>
<tr>
<th>Hackathon Name</th>
<th>Location</th>
<th>Dates</th>
<th>Event Organizer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spaulding Rehabilitation Hospital Hackathon</td>
<td>Charlestown, MA</td>
<td>September 2015&lt;br&gt;Friday evening 5:30pm – late, Saturday 8:00am-5:00pm</td>
<td>David Binder, Organizer &amp; Producer</td>
</tr>
<tr>
<td>Tikkun Olam Make-a-thon</td>
<td>Various</td>
<td>Typically over 72-hour a weekend</td>
<td>Michal Kabatznik, Former Director of TOM Global Operations</td>
</tr>
<tr>
<td>Triangle Health Startup Weekend</td>
<td>Durham, NC</td>
<td>August, 2014&lt;br&gt;Friday evening pitch session through Sunday evening demos</td>
<td>Brian Moynihan, Lead Organizer</td>
</tr>
</tbody>
</table>

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320 “About Us | What is a hackathon?” http://hackingmedicine.mit.edu/about-us/.
322 TOM Make-a-thons are held in various locations across the world. I was able to attend one held during the Ruderman Inclusion Summit in November 2017 and will draw on my notes from that event when appropriate.
“Teams organically form around the top ideas (as determined by popular vote) and then it’s a 54 hour frenzy of business model creation, coding, designing, and market validation. Beginning with Friday night pitches and continuing through brainstorming, business plan development, and basic prototype creation, Startup Weekends culminate in Sunday night demos and presentations in front of local entrepreneurial leaders for an opportunity for critical feedback.”

I used a snowball sampling method to find and contact the interviewees. Because of my involvement in disability activism in Philadelphia between 2012 and 2015, I was invited to help organize the 2015 Hack4Access, part of Philly Tech Week’s Random Hacks of Kindness campaign. In my work assisting that event, I learned of other disability hackathons as it became clear that the hackathon would become part of this project. I asked Faith Haeussler of Hack4Access to recommend other hackathon organizers. And during each interview, I asked for recommendations of other, similar hackathons.

The sample includes a diverse set of logistics that hang together under the name of a “hackathon.” In some cases, the hackathon was main event and raison d’être of an organization. In other cases, the hackathon was one element of a longer campaign.

The organizers in the sample used various operative terms to define the issue focus of their hackathon: disability, assistive technology, rehabilitation, health, and medicine were all terms organizers used to describe the focus of the work. We encountered a similar analytic problem of grouping -thons that both implicitly and explicitly reference disability that we found in the previous chapter. Here I’ve used the same metric: Drawing on the social model of disability, I include an array of cultural locations that are marked in contrast to able-bodiedness. For example, the Spaulding

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Rehabilitation Hospital Hackathon was situated within the field of rehabilitation science that generally avoids the word disability for its connotations of a permanent embodied experience, but the work to conceptualize hacking technologies for use among patients and consumers was similar to the work of the hack-athons more directly focused on “disability.”

Appendix 4A contains the email recruitment script and the protocol for the semi-structured questions. I followed the design methodology typologized by Tom Wengraf for semi-structured interviews. During the interviews, I was guided by what Wengraf calls the need for “double attention”: both listening to the informant’s responses to attend to what they are trying to communicate while ensuring that my protocol questions are covered in the fixed amount of time available.325

With one exception noted above, all interviews were conducted over the phone. With consent to be recorded from each informant, I transcribed the calls and collated them with my notes and data gathered from each hack-athon’s website and any reporting about the event.

10 interviews totaled 246.26 minutes of recording, with an average of 24.63 minutes per interview. The shortest interview was 14.23 minutes and the longest was 34.

**Key Features**

Having asked my informants about the events they organized, I widened my questions in each interview by asking about the form in general. I asked interviewees to tell me the essential characteristics of the hack-athon. What makes a hack-athon a hack-athon? Though this tended to come in the middle or end of the interview, we start with it

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here to shed light on this -thon form as it is imagined among those who have used it in their work. As mentioned above, there is little research on the hack-athon and so we offer this survey as some empirical evidence that is sorely missing – and to attend to the variance of the hack-athon that we will continue to discuss shortly.

Several organizers mentioned that the hack-athon is defined by a special time and place. “There is at least a day or some period of time where a bunch of people who are excited about the event are in one space working together,” said Jaya Narain (ATHack). “There's a lot of energy in that room and having a large group of people all working towards something at the same time in place.”326 This unique time and place serves the collaborative nature of the hack-athon that organizers cited as another key feature. “[Participants] put their ideas on the table,” said Ather Sharif (evoHaX), “and develop something by the end of it.”327

David Binder (Spauling Rehab) cast these features as reliant on an aesthetic of innovation. The hack-athon he says, should be “sexy” and “fun,” which means it must be held in the right kind of space. He toured the Boston Convention Center, he told me, but decided on an innovation lab one year and a co-working space the next because these spaces build a sense of pleasure and enjoyment in the pursuit of technical innovation.328

The focus on particular issues or problems – what Neil Giacobbi (Connect Ability) called “subject specificity” – was another important feature for some organizers. Developers were “paralyzed,” Giacobbi said, when presented with too large a scope for the event.329 The focus on certain design challenges in the marketing and recruitment for

the event thus helps manage what organizers saw was the need for many different kinds
of participants. Shriya Srinivasan (MIT Hacking Medicine) said the hack-a-thon “brings
together a diverse set of constituencies,” including varying degrees of technical and
subject matter expertise.\textsuperscript{330}

Several hack-a-thon organizers interpreted my question about the hallmark
features of the hack-a-thon in normative terms. While some responded explaining the key
features of their hack-a-thon or the hack-a-thon in general as they see it, others took the
opportunity to respond about what \textit{should} be the essential features of the hack-a-thon.

Faith Haeussler (Hack4Access), for example, lamented that too many hack-a-thons
sideline the lived experience of disability in the hack-a-thon. “Subject matter experts,” she
said, “need to be at the table from the beginning.”\textsuperscript{331} It should be disabled people’s
insight that leads hack-a-thon participants to innovation as opposed to technical experts
using the imagined experience of disability to design, pitch, and fund technologies that
disabled people may or may not desire.

Several organizers also mentioned that, as we will explore below, the hack-a-thon
is not a sustainable model for collaboration and thus its key features are also its
weaknesses. Michal Kabatznik (Tikkun Olam Makers) insisted that the hack-a-thon must
be one element in a longer process to sustain the work that might start there.\textsuperscript{332} Ather
Sharif (evoHax) told me that although hack-a-thons started with a focus on collaboration,
they moved to center competition, meaning participants formed teams and worked on
ideas in advance of the event. To combat this, organizers sometimes assign teams

\textsuperscript{330} Shriya Srinivasan, phone call with author, Aug. 31\textsuperscript{st}, 2017.
\textsuperscript{331} Faith Haeussler, phone call with author, Jan. 24\textsuperscript{th}, 2018.
\textsuperscript{332} Michal Kabatznik, phone call with author, Jan. 18\textsuperscript{th}, 2018.
randomly at the start of a hack-athon. Several organizers worry that this risks creating
time-limited cooperation that fails to produce meaningful technological insight in the
long run.

We can thus synthesize the key features of the hack-athon as articulated by the
interviewees in thus sample in the following way, noting that these do not produce a
coherent or complete portrait but nonetheless offer a helpful preliminary sketch:

<table>
<thead>
<tr>
<th>Key Characteristics</th>
<th>Enabled By</th>
<th>Threatened By</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unique time, unique place</td>
<td>Subject specificity</td>
<td>Unsustainability</td>
</tr>
<tr>
<td>with the stated goals of collaboration, innovation</td>
<td>Diversity of participants</td>
<td>Displacement of disability expertise</td>
</tr>
<tr>
<td></td>
<td>Aesthetic quality</td>
<td></td>
</tr>
</tbody>
</table>

We should note that the field of hack-athons relating to health, medicine, and
disability is something of a cottage industry. What we could call the “Boston story”
emerged within my sample. MIT was home to several disability-related hack-thons,
perhaps unremarkable considering the nexus of a college campus (hack-athons’
stronghold location type) with a history of STEM excellence. But MIT’s Hacking
Medicine bills itself as a service organization for hack-athons generally, beyond the hack-athon it produces each year.
As it turns out, another hack-athon in my sample, the Spaulding Rehabilitation Hospital Hackathon, was advised by MIT Hacking Medicine and relied on their documentation best practice models to get their annual event off the ground. While these documents shed some insight into how hack-athon organizers think of what the events should be (and, since the MIT Hacking Medicine consulting is available for a price, how these organizers see business opportunities in the hack-athon form), the field’s self-delegated service organization still doesn’t produce a level of standardization that amounts to reliability, as we’ll see below.

**Measures of Success**

How do informants understand and measure success of their events?

Stephanie Crouch (Lemelson-MIT) captured what many said when she reported that the production of “something new and novel” is the most important defining feature
of the success of a hack-athon. This is not an easy measure to capture, however. David Binder (Spaulding Rehabilitation) specifically cautioned against evaluating a hack-athon’s innovative ideas in terms of the amount of funding it received after the event because that process works on varying timelines in each case.

Instead, he measured the extent to which teams assigned to work together at the event were still working together 3, 6, and 12 months later, something he was encouraged to do by the MIT Hacking Medicine organizers. This, he says, is one way to capture the “networking and socializing” that several organizers told me was key to their events. Specifically, Faith Haeussler (Hack4Access) said, the goal of networking was to get the tech and disability communities to bridge the many divides that often separate them so that this work can continue.

Michal Kabatznik deferred the measure of success to the disabled “need-knower” who establishes the criteria for completion of a prototype or product. Without the long-term viability of an innovation as defined by the user who will use it, a hack-athon’s concluding demonstrations can leave the work unfinished or even deceptively finished.

Because of ATHack’s desire to “promote interest in [the space of assistive technology],” Jaya Narain reported that they design verbal feedback and survey protocols for collecting data about success. If participants report increased desire to pursue coursework or professional opportunities in assistive technology, the hack-athon

335 Ibid.
337 Michal Kabatznik, phone call with author, Jan. 18th, 2018.
succeeded, in keeping with ATHack’s devotion to the vision laid out by its late founder, a professor at MIT who passed away shortly after ATHack took off the ground.

None of the hack-athon organizers I interviewed defined success in terms of the management of a collective physical effort or endurance. Unlike Coleman’s portrait of the hacker conference ritual as a lively affair of the body – consuming, sleep deprived, and intensely social – hack-athon organizers instead thought of the success of their work in terms abstracted from the body and indeed not reliant on it.

**Participant Roles**

Within these reports about what success is and how it is evaluated, references to “the community” were frequent and salient. Often, disabled participants are automatically assumed to be part of, or constitute entirely, “the disability community.” Though at first blush this might seem like a verbal shorthand not worthy of much attention, I think in fact it speaks to a common imagined binary between able-bodied technical experts and disabled users of the experts’ design ideas.

Organizers have an array of terms for disabled participants in their events, each reflecting a hack-athon’s unique approach to disability in a general sense. Neil Giacobbi (Connect Ability) told me the publicity and success of his event was predicated on what they called the “exemplars” in their campaign. The Connect Ability competition began with videos about 4 disabled people in New York City who “imagine how transformational technologies promise to improve their lives, and the lives of millions.”

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“There is a tendency with technology design for the developers to go off and create a problem,” Giacobbi said. But the limitations in Connect Ability set parameters from the start “that transformed the character and personified the humanized initiative in a way that a prior competitions never achieved.” Similarly, Tikkun Olam Make-athons refer to disabled participants as “need-knowers,” specifying that the designation of what is necessary for a team’s work should begin with the disability experience.

MIT’s ATHack refers to its disabled participants as “co-designers,” but during my conversation with Jaya Narain, she often referred to the event’s need to interface with “the community” and how being able to interact with “the community” was the real measure of success for her event. I find scant description of the way hack-athon organizers invite disabled people to participate, and even less about how they are invited to be “co-designers.” In many cases, the “co-designing” is ironic when, at the end of a hack-athon, the able-bodied hackers take their spot on a stage during the concluding demonstrations and ask their disabled “co-designer” to perform the way their prototype operates.

In general, hack-athons rarely imagine that disabled people and technical experts might actually be both. Exceptions prove the role: this trend is in fact what inspired Ather Sharif to found evoHaX in Philadelphia. The refusal of pity narratives around the possibility of technology is what motivates Sharif to center accessibility in his planning. This is shared at the other Philadelphia hack-athon, Hack4Access, when Faith Haeussler planned several focus groups with disabled people she calls “subject

matter experts” in order to source specific design concerns to present to the participating hackers as a way of undoing the implicit ableism she sees many hackers ascribe to.³⁴²

Designating “the community” of disabled users of technical solutions as apart from and reliant on the class of technical experts doing the hacking at hack-athons is one way hack-athon organizers often recapitulated some of the pity roles we’ve seen in other-thon rituals, an important continuity across our cases. Disabled people are assumed to be in need and they ultimately justify what Irani would call the subject formation at work. The moment when nondisabled hackers pitch their idea at the concluding presentation to judges can be understood as the time when disabled people form the substrate on which nondisabled experts build their own literal and figurative capital in tech industries.

**Repair & Cure**

Theories of technological change are often modeled in hack-athons without explicit articulation. In disability hack-athons, these are particularly important to attend to since they offer a glimpse into the way that hacking and the body are imagined to interact during the event.

Tikkun Olam Makers are a particularly instructive in this regard. *Tikkun olam* is a Hebrew phrase that means, Michal Kabatznik told me, “repair the world.” When I attended a TOM make-athon in November 2017, I heard the phrase used several times. What, however, does this refer to? Is what needs repairing the world of ableist exclusion? Is it disabled people themselves that need repair, aligning with a medical model of disability that activists have fought to overthrow for decades? Is repair a one-time event that returns a problem to its original state? Does it strengthen the object of repair? Is it an

ongoing practice? TOM maintains the ambiguity of this phrase well, which is key the amount of press their organization has received. Because of the decentralized way their events work, organizers and teams decide what they are “repairing” in their particular sites, according to the decision-making process of the groups that assemble for the event.

Disability scholar Alison Kafer calls the “curative imaginary” the hope, often lodged at the heart of contemporary technoscientific projects, that we might eliminate disability through technical means. Though disability in fact proves to be a natural and permanent feature of the human experience, ableist desires for a world without the supposed pain and suffering of disability carry a unique and powerful imaginative force. Thus we might now consider whether it is merely coincidental that disability is a stable and popular issue focus for the spate of hack-a-thons organized around the U.S. each year.

The relationship between code as a system for applying computation to all bodies and the incarnate body as that which resists code’s drives for abstraction produces the pleasure, frustration, and affect of hacking that is condensed in the hack-a-thon form.

As software production continues to model news ways of conceiving of labor, the hack-a-thon has become a site for ritually enacting the body as a the substrate for technology’s proofs of concept. If hacking can repair or cure the body, it can claim a new digital circuit of technical knowledge production that advances medical and literate systems of control. From this vantage, it becomes clearer why the requirement of endurance and the focus on disability might make a hack-a-thon the quintessential form for imagining technologies and bodies together – even when hack-a-thons fail to produce the kind of embodied transformation we found in the previous case studies in this project.
The -Thon Now

When I ask Neil Giacobbi (AT&T Connect Ability) about the rise in popularity of hack-athons in recent years, he demurs. Hack-athons reached their peak, he estimates, around 2010 but have been waning ever since. This names an important trend in my interview sample: most hack-athon organizers are not still organizing annual events. And if they are, they have made significant changes to their structure.

They say the hack-athon doesn’t sustain the work of producing sophisticated technical solutions. Teams disperse, the prototypes don’t work, and the inertia evaporates. The hack-athon form may have been useful as an anchor in their event marketing – the play of the portmanteau – but it didn’t make a meaningful embodied ritual.

When the Muscular Dystrophy Association announced the end of the telethon in May of 2015, it cited the success of the ALS Ice Bucket Challenge as proof of a changing environment for charity campaigns, one that now demands a sophisticated understanding of how social media propagate giving appeals. The telethon gave way to a different kind of giving campaign, one that now enrolled the body not in a marathon but in a rush of freezing water. Textual propagation alone would not do: the body had to be under the ice bucket as the camera captured the thrill. So while the endurance is not necessarily in how long a host can perform or a viewer can watch or a participant can dance or walk, there is nonetheless an essential referent in the non-falsifiable body at work.

It seems the hack-athon shows us what happens when the -thon form loses its tether on the central role of the body in endurance ritual performance. If we had to guess, we might say that the next sensational charity giving campaign – so often suggestively
related to disability – will find a reliable anchor in the body, something we now understand as key to the histories of -thon forms we’ve traced throughout this project.
CONCLUSION: DISABILITY & ASPIRATION

I began this project thinking about how ableism maintains itself. It seems that maintenance is an important part of ableism – a system of keeping some assumptions intact, subverting inconsistencies, and enforcing the illegibility of disability. As the visibility of identity politics roils the contemporary political and affective landscape, I wonder, with many other disability scholars and activists, why and how disability often remains a subverted heuristic.

And yet for those who inhabit and deploy the word “disability” in understanding the world, there is no shortage of instances where disability is at work. So we face a unique situation: many don’t seem to notice disability anywhere while others of us can’t help but perceive it everywhere.

Disability scholar Tobin Siebers would say this is a hallmark of what he calls the “ideology of ability.” Ideology, and its allied concepts of hegemony and domination, among others, help us name the ways silences and lacunae are motivated, the way contradictions get covered over, the way groups decide not to disagree about some things.

If these were the things that I wanted to try to understand, it was clear that I would need to look at the categories understood as dominant, normal, natural, unmarked, and ordinary. This would become a study of disability as it is sidestepped, flattened, and overridden. Disability seems written in negative space more than it is explicitly evoked.

I was thus in the position of needing to find a tool in the system of the status quo, one that I could isolate, examine, and historicize. This is how I came to focus my work on the marathon form, a technology that is in the business of producing subjects, rituals, and
feelings through and about disability without, often, speaking its name – or without even seeming to be overtly political.

But what I found even more interesting than the marathon itself is its apparition. Not the marathon that involves traversing 26.2 miles, but the marathon as a floating signifier in the temporal extension and often-vigorous collective physical effort in other activities. Most marathons in the U.S., I now say, do not involve running. They’re the marathons of hair cutting, roller skating, bowling, reading, biking, and on and on and on and on and on and on.

The preceding chapters have centered on what I’ve argued are the most salient, popular, and important cases in the mosaic of -thons in the U.S. in the latter part of the 20th century. For many of their participants, these are background noises (perhaps literally in the case of the telethon). They’re things you may have spent a few Saturday mornings a year at. They’re serious enough to command participation but often not serious enough to maintain vivid memory – or sustained scholarly attention.

In this final chapter, I want to reflect back on the portrait of the -thon I’ve offered in the previous chapters, spending some time summarizing and connecting the chapters that have largely used different methods in different times and space, with different actors. What they share, I’ve offered, is their construction of a dominant category of able-bodiedness, especially as they rely on the imaginations and valences of endurance.

But I’d like to spend the latter half of this chapter then thinking with instances of the critical categories that have cropped up near the -thon. Have there been any disability-affirmative -thons? Is that a contradiction in terms? Throughout my work on this project, I’ve found many powerful art objects that have undertaken work I see as allied with my own, projects that similarly hope to show how the -thon is a tool that enables ableism.
The latter half of this chapter meditates and *breathes* with these projects, forming what I hope is a contemplative counter-ballast to the telethon, walk-athon, dance-athon, and hack-athon forms.

**Chapter Summaries**

In chapter 1, we established the working parameters for studying the *thon. While the suffix has enjoyed robust circulation in portmanteaux and colloquialisms, it was necessary to name specific recurring elements of a -thon in order to design ways to studying it. We defined the -thon as incorporating: 1) collective physical activity, 2) temporal persistence, 3) performance of conspicuous endurance, and 4) moral enactment. These elements are divine from Roy Rappaport’s neo-Durkheimian emphasis on the role of the body and embodiment in ritual activity.

We then assigned the -thon the status of ritual, evoking a long legacy of communication studies scholarship that theorizes formalized collective behavior. *Thons, we said, are pedagogical units in the way they condense cultural affect and marshal bodies in physical activity. We thus showed the rich intersection of ritual with disability studies at which the -thon lies.

In the latter part of chapter 1, we also offered empirical data from two months of Google-indexed content alerts of the use of the -thon suffix. We collated 760 -thon events that occurred across the U.S., mapped them, and randomly sampled within them to produce interview data for a study of contemporary -thon organizers. In interviewing 25 organizers, we gained insight into the variance of -thon event logistics and the variance of their stated motivations and goals. The content alert and interview data thus offered a portrait of the *thon as it surrounds us today.
We began our study of specific and demonstrative cases in chapter 2 with the telethon, a -thon with a unique popularity and longevity. Though this chapter drew on over 150 hours of various telethon content, we focused on the Jerry Lewis MDA Labor Day Telethon because it was so widely viewed and because it captured some of the format’s most telling details.

We considered the telethon’s propaganda-of-the-deed, noting Lewis’s out-of-breath performances enrolled at-home viewers as participants mirroring his work with their donations. We looked at the telethon’s script of endurance in battle terms, framed as a fight against the clock and also against disability itself. We ended this chapter by proposing to understand the telethon ritual in terms of its formal modeling of a “moral prophylaxis” against disease a disability, inflected by imaginations of the proper role of generosity, voluntarism, and apolitical healthcare management.

In chapter 3, we continued our investigation of the moral enactments of endurance in the dance-athon and walk-athon. We located them in the 1970s for the purposes of the study, a decade when they saw their popularity swell and against important developments in the formation of a nonprofit industrial complex that found them to be reliable fundraising tools.

We began with a close reading of They Shoot Horses, Don’t They?, the 1969 dance-athon drama film adaptation of Horace McCoy’s 1935 novel. We read the novel through disability, finding an aesthetics of eugenics that centers the novel and film’s tension on the legitimation of the murder of its crip figure. The dance marathon becomes the contest of society itself, I argue, and elimination is its cardinal moral directive.
We then move to a content analysis of 2,885 U.S. newspaper and periodical mentions of dance- and walk-athons in the 1970s, sourced from the ProQuest Historical Newspaper & Periodical Databases. We discover several trends in coding the data, chief among them that -thons related to disability were prevalent in reporting: 61.6% of dance-athons and 53.4% of walk-athons. We then focused on particular sources within the sample that round out the portrait of these forms in the 70s, pausing to consider the role of what we called “joyful anguish” in the writing and photography in these newspaper and periodical sources. The capacity for the enduring body to amass charity donations through pledge and sponsorship models thus makes these forms emblematic of what is often referred to as neoliberalism.

In chapter 4, we follow the mosaic of -thons into its most contemporary popular incarnation, the hackathon. We trace several dis/continuities with the earlier cases, showing how the activity of hacking (often as the production of software code) activates key questions about embodiment and performance that both extend and torque the valences of endurance we discovered in earlier chapters. We find that endurance has a unique role in the ethics and culture of hacking, which lacks an important analytical emphasis on embodiment.

We relied on interview data with 11 disability hackathon organizers to both flesh out the empirical evidence available for the study of the hackathon itself and to demonstrate how the hackathon formalizes values about nonnormative bodies at a moment when digitization transforms how we imagine innovation, technology, and change. We considered how the rise of thinking about society itself as a programmable entity emerges in the hackathon form that relies on disability as a substrate for proving
concepts of innovation, which is often on display in hack-athons that relate to disability. We also found, however, uses of the hack-athon format that signal different ways to position disability as the site of knowledge production, indicating new assimilations of the disabled body in the imagination of a technological society.

Taken together, these cases offer a portrait of the -thon ritual tightly embedded into some of the most pressing questions about America in the latter 20th century. They show that the meanings of endurance run deep and attach to ideas of independence and autonomy, charity and civic engagement, the nation, and, of course, dis/ability. The –thon form condenses and enacts moral valences of the body, encoded by an array of affects around charity, generosity, philanthropy, physicality, individualism, sentimentality, altruism, and compassion. The twinned social and physical threat of disability is fixed without speaking its name.

I use dis/ability to signify the way that -thons rituals often do not name disability as such. They often direct our attention away from disability or attempt to stabilize a diminished understanding of it. They use ritualized celebrations of ability in order to make a dark specter of disability that supposedly motivates the moral goodness of American group formation. They paint disability with negative space.

It's important to note, then, that this work is animated by the desire to show how -thons attempt to make natural certain distinction between their participants. In order to show the contingency of these roles, we’ve needed to take their designations quite seriously. But the ultimate analytic goal here is to denaturalize the workings of ableist ritual role assignment, not elevate them to anything near an ontological status. At the
conclusion of this project, then, we can pause to consider just what it means to unveil a dominant category as effortfully produced and not, in fact, as invisible or pre-ordained.

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In the digital installation What is What commissioned by Creative Time in 2003, Bill Shannon defines phenomena that help name aspects of disability experience. He defines an entry called “peripheral fluctuation” as “the experience of seeing in the periphery of one’s vision a constant fluctuation of the status of where people are looking.” He continues, “[I]t’s inappropriate to stare directly at someone but as soon as you are perceived peripherally as having passed, people will stare.”

Fig. 5.1: White text reads “BILL SHANNON (AKA THE CRUTCHMASTER) / WHAT IS WHAT / NEW YORK CITY, 2003.” At the corner of 6th Avenue and Broome Street in Manhattan, Shannon dances on a sidewalk with his crutches in a white track suit, facing away from the camera. A woman who has just passed him on the sidewalk turns her body and head to look back at him.

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-Tons can be conceptualized like these fluctuations. They encourage us to look straight ahead but allow a peek at the periphery, at disability, every so often. They manage disability as circumferential, the thing that often defines a border, but not the center. The fluctuation is important. Because the gaze is directly not at the thing that draws attention, disability is hard to pin down. It hovers in the corner.

What happens at a 5K “race for the cure”? Disability activists have rarely named these kind of civic gatherings as a site for the production of ableism. And when they do resist the events, as in anti-telethon activism discussed in chapter 2, they claim it’s the representation of disability that is so troublesome. Here I’ve tried to go deeper: it’s the way that disability charity work enfolds the sacrificial elements of endurance in the mode of fitness that places disability, always fluctuating, in the periphery where it can more easily be managed by not being named.

I’ve often wondered if, now at the end of this project, it helps to cast -thons and their popularity as ableist. If the -thon is a tool for maintaining able-bodiedness at the center of the charmed circle of American life, wouldn’t it be helpful to reframe their work at making disability imperceptible? If we commit ourselves to the liberation of disabled people, shouldn’t we call -thons ableist?

I think this cuts the Gordian knot when the answer is trickier. -Thons are certainly in the toolkit of American ableism. And many of them are explicitly ableist, especially when disabled people have no meaningful way to engage in the event, have had no place in the decision-making processes, and when pity courses through a space like fast-moving vapor. But from an analytic view, I believe -thons are the symptom and
convenient ritualization of ableism. Are -thons ableist? They shore up ableism. They deliver ableism. They maintain ableism. They secure the embodied ideology of ableism.

People ask me this question about -thons as ableist because they want to know how to feel about them, having grokked the critical perspective this project has tried to offer. But, I say, there’s nothing I can do to help us feel resolved about -thons. They are tricky things. They condense intricate currents of American identity politics. They cannot be met with a monolithic response, which threatens to undo the analysis I’ve offered here.

One place to look for ongoing interrogation of the -thon form is a less popular but potent kind: -thons that are critical of the -thon itself. As I’ve logged and followed -thons in the U.S. in the past several years, I’ve noticed that every so often, there emerges a -thon that uses the formal elements of the suffix – the performance of conspicuous endurance perhaps most of all – to turn a critical sense back on the form.

Perhaps the most important and memorable instance of this was the Capitol Steps Crawl in 1990, discussed in chapter 1, where disabled activists climbed the stairs of the Capitol in order to demonstrate the hegemony of ableism. What they demonstrated, I believe, is that marathons are ordinary events for disabled people: the seemingly endless commute when a wheelchair user discovers a broken elevator in a subway station, the walk down a sidewalk for a person using a walker when snow has only been shoveled in a thin path or not at all, the byzantine process of securing accommodations for a student with nonapparent disability who is met with skepticism from professors and student disability services staff. And these marathons endure, 28 years after the passage of the Americans with Disabilities Act that the Capitol Crawl helped secure.
It is important to note that these marathons are *designed* by the shape of ableism. Much can be said of “crip temporality,” the concept in disability studies for the ways bodies and minds experience time differently when a chrononormative drive imagines time as standardized and even. But the marathons I’m thinking of are the product of an inaccessible world. They are *made* marathons. If the -thon as I’ve traced it in the preceding cases is often celebrated for its voluntary and public character, the shadow -thon for disabled people is involuntary and so often enforced as imperceptible. The experience of disability in an ableist world is often that of a -thon.

NOLA to Angola is an annual, three-day, 170-mile bicycle fundraiser. The ride begins at Orleans Parish Prison in New Orleans and finishes at the Louisiana State Penitentiary in Angola. “The ride draws attention to the great distance and many barriers separating people on the inside from their family members,” says the event’s website.\(^{344}\) In a city that incarcerates people at almost twice the national average,\(^{345}\) the 170-mile distance to Angola makes visitation a serious obstacle to families on the outside. Along the ride, organizers and community leaders speak to riders about the effects of incarceration, including “environmental racism in the petro-chemical corridor, police brutality, prison reform organizing, re-entry advocacy, and lack of access to legal services.”\(^{346}\)

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\(^{346}\) “About NOLA to Angola.”
This bike-athon uses the marathon format to document and demonstrate the length of the distance between incarcerated people and their support systems. The bicycles become the instrument for measuring and understanding this otherwise abstract sense of space. And the event organizers use the rest stops as pedagogical moments, to bring participants into the scene of incarceration’s widespread effects. By the end, the triumph of finishing the bike-athon and raising money to support the bus service that transports families from New Orleans to Angola is met with a deeper understanding of the injustices that have created this marathon.

As part of his 2012 Fire Island Artist Residency, trans artist Kris Grey staged a four-hour durational performance in the pool at the Ice Palace in Cherry Grove. Interested in the decades of queer history on Fire Island, Grey spoke to many long-time residents and was struck by one story in particular. During the periodic raids of the establishments on Fire Island in the 1960s, one resident evaded arrest, the narrative goes, by running through the Grove and into the bay. There he submerged his body in the dark water for hours, using a reed to breathe and remain invisible from land. Grey was struck, he writes,
“by the images in the story and what they tell us about surveillance, safety, visibility, and queer experience.”

Figs. 5.3 & 5.4: Two images of Kris Grey’s “(Sub)merge.” On the left, an image of Grey alone in a green-lit pool, distorted by the diffraction of light in the water, with the Ice Palace and people at the bar in the background. On the right, a tighter image of Grey underwater as the sun sets, with a clearer shot of the reed in his mouth extending to the surface of the water.

In “(Sub)merge,” Grey stages a four-hour durational performance from 7-11pm under the water, using only a reed to access air at the surface. Because the performance required an empty and calm pool, the work became part of the bar’s evening, inviting onlookers to ask about the performance and opening itself to being ignored or overlooked as the stories of queer elders often are on contemporary Fire island.

Grey uses his body as the medium for restaging the story’s involuntary marathon of escape. He is interested in the concealed effort, the lengths the story’s character went to avoid capture. Thus, the -thon Grey creates in this work is a literally submerged queer experience.

marathon of risk and vulnerability in the pursuit of ultimate safety. Again, the -thon, here with only one enduring body that enrolls some parts of an onlooking participants, turns back to question the demands of the -thon itself.

Inspiration

There’s an eddy of news stories after each major city marathon that focus not on the first finishers, but the last. After the 2017 New York City Marathon, The New York Times published a video called “Last, Not Least, at New York’s Marathon.” In black and white tones evocative of the post-sunset scene when the race’s last finishers arrived in Central Park to collect their medals, an announcer and spectators cheer wildly. A woman kisses the ground, another cries. A woman who organizes a project called Project Finish talks about her work to support late-game finishers. There is more crying.

And then a Black man arrives in a manual wheelchair. He smiles widely as walkers flank him with signs say that “DAVE FRASER.” He is the final finisher of the race and several cameras follow as he pushes across the line. In the following days, the headlines celebrated his accomplishment: “Marathoner’s Uphill Battle,” “Man with Cerebral Palsy Completes 10th Marathon,” “Simply Inspiring: Watch Dave Fraser Complete His 10th Marathon.”

Dave Fraser’s finish was all the more “inspiring” because he finished in a wheelchair. Inspiration is a dominant category in popular discourses of disability. “Inspiration porn” is the term many within the disability community use for these kinds of stories. Marathon inspiration porn is a special kind. It makes “inspiration” literal.
Is inspiration the sharp intake of air that precedes the well of tears? Is it the breath someone pulls in before gushing about how brave and heroic the disabled athlete is?

In his 1999 essay “The Mountain,” Eli Clare renders a material and metaphorical summit that “looms large in the lives of marginalized people.” The mountain is what disabled people must climb and their toils are narrated as part of the “supercrip” stereotype: either disabled people doing nothing remarkable and being celebrated like heroes for it or disabled people literally climbing mountains and demonstrating to able-bodied people that if he could do it... The mountain is the site of literal inspiration, the harsh intake of labored breathing. And it’s from this material body that we get the symbolic ones, the ones that become tear-jerking headlines. This duality of the mountain is its material and metaphorical status, both at once.

Thus the sounds of heavy breathing in the news footage of the 1990 Capitol Crawl become even more complex. To some, these are the sounds of pathetically heroic disabled people showing how impressive it is to persist when it is supposedly so awful and painful to live as a disabled person. To others, the breathing is the sound of ableism itself.

Aspiration

I need a tear gas mask more than I need a collar
to be able to do the work that I feel called to do.

—Rev. Osagyefo Sekou

It is not because the Indo-Chinese has discovered a culture of his own that he is in revolt.
It is because ‘quite simply’ it was, in more than one way,
becoming impossible for him to breathe.

—Frantz Fanon

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Since the death of Eric Garner, whose asthmatic breath was used to justify his murder, declarations of the inability to breathe have come to condense the feeling of injustice in the U.S. “We can’t breathe” was a key phrase in protest signs and chants around the country following Garner’s death. Dayshen McKenzie, a Black teen on Staten Island, died in June 2016 while fleeing a mostly white group of men shouting racial slurs. Michael Sabbie died in a for-profit prison when guards sprayed him with pepper spray on a concrete floor and then piled on top of him. “I can’t breathe!” he said. “I can’t breathe, sir. Please! Please!”

The “we” in the chants and signs of “We can’t breathe” index a collective of disinvested and marginalized people whose breaths are snuffed out and ignored, laboring under the weight of domination. It becomes a way of thinking of aspiration in the literal sense: how one is able to breathe becomes intimately connected to the quality of one’s aspirations, one’s sense of a future where hope can happen.

Marathons and protest marches don’t seem to have much to do with each other. But I hope this project has shown that they’re in fact intimately connected. The long-distance running marathon and the spate of -thon events it spawns manage a civic breath,
the idea of American moral fitness. But the labored, involuntary breathlessness is enforced as invisible, outside the charmed arena of the status quo.

This project has grown from the curiously dichotomous definition of the word “aspiration,” about desire and about breathing. Perhaps they’re more connected than we might realize at first, because the extent to which individuals can freely aspire in and out of their bodies determines to some extent what they can aspire to. What intrigues me about breathing is that it disappears in comfort. And when we notice the breath, it’s often that we’re applauding it (the conspicuous endurance of able-bodied -thon participants) or we’re flattening it (the breathiness of mundane marathons in the experience of ableism taken as the need for charity). Aspiration becomes, then, a metric and heuristic for understanding the attempts to manage bodies literally and symbolically. We focus on the breath to know when and where it gets silenced and when and where it gets exalted.

Out of breath for better aspirations on the horizon. A hope for suspiration.
APPENDIX 1A: *Thon Events

The following is a list of the names and frequencies of the –thons I cataloged, from Google Alerts on “**thon” during April and May 2015.

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APPENDIX 1B: Interview Recruitment

This is the email used to recruit participants for interviews:

Subject: ____-a-thon – Interview Request

Hello——

My name is Kevin Gotkin and I'm a researcher at the University of Pennsylvania currently studying all forms of marathons. As part of my research, I am interviewing those involved in organizing community events like walk-a-thons, bike-a-thons, and adopt-a-thons around the U.S. Last year, I came across the ______ that your organization held and I'm hoping to talk with someone who helped plan it. I'm interested in where the idea for a -thon came from and how the event was organized. I don't expect the call to take more than 15 minutes of your time. Please let me know if you'd be willing to chat with me and I look forward to hearing from you. Thanks!
APPENDIX 1C: Interview Sample Information

Below is a screenshot of the responses to my request for interviews from 50 random sampled thons from my data pool. Of the 50 requests sent, 24 were successful in recruiting interviewees, and 2 organizers declined to be interviewed.

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APPENDIX 1D: Interview Protocol

While I varied some aspects of my interviews, the following is a list of questions I asked all my interviewees.

How do I pronounce your name?

Can you tell me a little bit about your event?

Why did you want to make the event last so long?

Where did the idea for a –thon come from?

Did you have other names or ideas in mind for the event?

Are there other events you had in mind when you were planning the event?

What the things that helped make this event successful?

Did the name of the event help make it successful?
APPENDIX 2A: Archival Material

For as popular as the telethon format was over the course of the latter twentieth century in the U.S., there is no home for telethon content. Many of the telethon-producing disability organizations jealously guard what archives they have because they recognize the widespread criticisms that emerged around many telethons’ representations of disability. When I reached out to the Muscular Dystrophy Association and almost all of their regional offices, I was directed to the Vice President of Multimedia Services, who curtly told me that “For various legal and other considerations, we’re not in a position to release the footage.” Some weeks later, an anonymous employee at the national office emailed me to say that the end of the telethon in 2015 was a deeply controversial issue among those at the headquarters and as a result they rarely discuss the telethon’s legacy. This was not news to me, having understood by then that the same cunning public relations teams that innovated the telethon form itself have given way to a new generation of fundraisers who are particularly sensitive to telethon criticism.

However, I was able to discover an archive of telethon footage from another disability organization, the United Cerebral Palsy of Middle Tennessee. In addition to being more decentralized than the MDA regional offices, UCPs also tended to support the independence and community-living of people with disabilities more than the MDA. This is reflected in the telethon content I was able to digitize and view at the UCP offices. As I reached out to all the UCP regional offices, I found that a number of them has similar archives in their offices. Unfortunately, many of these archives are comprised almost entirely of recording masters, often on formats like U-Matic and Betamax, that require studio-grade players in order to view.
Despite the lack of availability of telethon content from the very organizations that produced these programs, there are a number of media archives that have acquired footage over the years. The estate of Jerry Lewis recently donated a rather large amount of film reels from MDA broadcasts to the Library of Congress and I was able to view most of it there.

I was also able to acquire telethon material from the collectors’ market after having corresponded with a number of telethon fans whose writing and YouTube content demonstrated they had archives of their own.

What is missing from the list of primary sources below is a trove of content uploaded to YouTube. I don’t include this list here because a) I have watched hundreds of videos, much of which is incredibly repetitive, and have cited the most important findings through the chapter, where relevant and verifiable and b) because I cannot verify myself that the user-generated titles and descriptions of the content are accurate. That said, I made extensive use of the YouTube Data API in order to search with more precision than is offered by the site’s front-end user interface. An enormous amount of content has been uploaded, mainly by people who had recorded telethons on VHS and decided to digitize certain moments. (Which clips users found to be salient enough for uploading to YouTube is perhaps the subject of another study, though I was aware that in many cases uploaders act as curators and sometimes editors of the footage.) I corresponded with a number of popular telethon uploaders and confirmed my inclination that these users tend to be avid supporters of Jerry Lewis and telethons in general.

In the list below, I detail the roughly 153 hours and 20 minutes of content I have watched during the research for this chapter.
Paley Center for Media, New York City

Visited April 19-20th, 2015 and May 17-18th, 2015

Easter Seals Telethon, 1978

1 hour of digitized video (first hour)

Catalog ID: B:93940

Muscular Dystrophy Association Telethon, 1990

2 hours of digitized video (final hours)

Catalog ID: B:45356 & B:45358

TOTAL HOURS: 3 hours

Paul Longmore Papers, San Francisco State University

Visited June 22 – 27th, 2016

Arthritis Foundation Telethon, 1994

1 8-hour VHS tape (entire broadcast)

Catalog ID: Box 140

Muscular Dystrophy Association Telethon, 1990

1 8-hour VHS tape (final hours)

Catalog ID: Box 140

Muscular Dystrophy Association Telethon, 1992

1 6-hour VHS tape (first hours)

Catalog ID: Box 140

United Cerebral Palsy Association Telethon, 1992

1 8-hour VHS tape (first hours)

Catalog ID: Box 140
Muscular Dystrophy Association Telethon, 1995

1 6-hour VHS tape (first hours)

Catalog ID: Box 140

Muscular Dystrophy Association Telethon, 1997

1 8-hour VHS tape (first hours)

Catalog ID: Box 140

TOTAL HOURS: 52 hours

Moving Image Research Center at the Library of Congress

Visited April 18 – 20th, 2016

Television Party for Muscular Dystrophy, 1953

2 60-minute 16mm reels

Catalog IDs: FBD 3027 & 3028

Jerry Lewis Thanksgiving Party for Muscular Dystrophy, 1957

17 30-minute 16mm reels\textsuperscript{351}

Catalog IDs: FCB 8635 – 8651

Muscular Dystrophy Association Telethon, 1968

2 60-minute 16mm reels (first and last hours)

Catalog IDs: FBD 3032 & 3033

Muscular Dystrophy Association Telethon, 1969

2 60-minute 16mm reels (first and last hours)

Catalog IDs: FBD 3034 & 3035

Muscular Dystrophy Association Telethon, 1970

\textsuperscript{351} The final reel, FCB 8651, contains less than the others, about 10 minutes of the final minutes of the broadcast.
2 60-minute 16mm reels (first and last hours)

Catalog IDs: FBD 3036 & 3037

Muscular Dystrophy Association Telethon, 1979

2 60-minute U-Matic videocassettes (12pm-1pm & 1pm-2pm)

Catalog IDs: VBX 7072 & 7073

**TOTAL HOURS: 18 hours and 10 minutes**

United Cerebral Palsy of Middle Tennessee, Nashville

Visited regularly from January – March, 2016

Weekend With the Stars Telethon, 1986

5 1-hour VHS tapes (first hours)

Weekend With the Stars Telethon, 1987

2 6-hour VHS tapes (first hours)

Weekend With the Stars Telethon, 1988

2 6-hour VHS tapes (final hours)

Telethon Mini-Docs, 1989 (pre-produced human-interest segments)

1 30-min VHS tape

Weekend With the Stars Telethon, 1997

1 6-hour VHS tape (first hours)

Weekend With the Stars Telethon, 1998

1 6-hour VHS tape (first hours)

**TOTAL HOURS: 41.5 hours**

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352 We can see this local archive as representative of other organizations’.
Acquired from collectors

Digitized May 2016

MDA Labor Day Telethon, 1974

2 hours (first hours)

MDA Labor Day Telethon, 1976

6 hours (sample from throughout the broadcast)

MDA Labor Day Telethon, 1977

6 hours (sample from throughout the broadcast)

MDA Labor Day Telethon, 1978

10.5 hours (sample from throughout the broadcast)

MDA Labor Day Telethon, 1979

6.5 hours (sample from throughout the broadcast)

MDA Labor Day Telethon, 1980

7.5 hours (sample from throughout the broadcast)

**TOTAL HOURS: 38.5 hours**

---

353 I bought DVDs of these programs, which were transferred from their original medium (likely video reels) to VHS and finally to DVDs. Because the MDA does not look favorably on the circulation of their copyrighted material (even for fair use purposes), I am not printing the name of the collector I purchased from.
APPENDIX 2B: Sample Play-by-Play

The 1976 MDA Telethon was a special broadcast. It was one of the most watched telethons of all time, reaching over 80 million people. As I have mentioned in parts of this chapter, claims on telethon ratings, including the ones during the 1976 broadcast itself, are tenuous due to the unique length of the format. But we know that what made the 1976 program so spectacular was the emotional reunion of Dean Martin and Jerry Lewis, brokered by Frank Sinatra live on stage without the prior knowledge of Lewis. Martin and Lewis had a very public split nearly 20 years prior after enjoying great success as a comedic duo (and campaigning for MDA in its very first years of public fundraising). In 2011, an article in The Atlantic remembered the reunion as “one of the most famous moments in television history,” which is how many cultural critics have characterized the event.

In order to give a fuller portrait of telethon content, I include here a sample play-by-play from the 1976 broadcast. I acquired this footage from a collector in May 2016 and the footage samples rather evenly: 6 hours from the 21.5 hour-long broadcast. If my analysis in this chapter draws on descriptions of particular performances on telethons, here you can find a reduced version of what they would have been like to watch continuously:

<table>
<thead>
<tr>
<th>CLOCK TIME (Central Daylight)</th>
<th>TIME ELAPSED</th>
<th>SEGMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00pm</td>
<td>0 minutes</td>
<td>A camera follows Lewis in his trailer and backstage as he prepares to start the show, set to a pre-recorded Lewis singing about how he feels “before the show begins” (the song’s refrain). At one point, Lewis wipes his face with a white towel.</td>
</tr>
<tr>
<td>8:01pm</td>
<td>1 minute</td>
<td>Ed McMahon introduces the show with a list of talent to come, then introduces Lewis.</td>
</tr>
<tr>
<td>8:03pm</td>
<td>3 minutes</td>
<td>Lewis sings an opening song with lyrics by Lil Maddis encouraging audiences to donate.</td>
</tr>
<tr>
<td>8:05pm</td>
<td>5 minutes</td>
<td>Lewis delivers his opening monologue, mentioning over 100% of pledges last year came in to total over $20 million in donations and his goal this year is one dollar more, wants to be able to cure MD during the America bicentennial.</td>
</tr>
<tr>
<td>8:08pm</td>
<td>8 minutes</td>
<td>Lewis introduced his “pussy cat” and “super gent” and “anchorman” Ed McMahon, the two have brief banter, Lewis mentions Chad Everett and David Hartman will also anchor to “help [him] breathe” during the show.</td>
</tr>
</tbody>
</table>

Lewis introduces poster child Lisa Cagle by singing “Wait Till You See Her” (by Richard Rodgers first introduced in the musical By Jupiter and later covered by singers like Ella Fitzgerald and Frank Sinatra) with rewritten lyrics about Lisa’s hobbies and disability with a split screen of her face looking on.

Lewis brings Cagle on stage for some banter, then talks about strides the telethon has made in the 26 years he has been involved in fundraising for the MDA and asks for audiences to call in pledges to help the 135,000 people affected by MD.

Lewis introduces an opening act good luck charm Vikki Carr who sings “Puttin’ Myself in Your Hands (Gettin’ Ready to Move).” After, she speaks about how important the telethon is and offers a donation appeal in Spanish. Then she sings “You Will be My Music” by Joe Raposo and performed by Frank Sinatra.

Lewis praises Carr and remarks on how put together the on-stage volunteers look at the start of the show, says in 7 hours they will be “wilted pieces of Corn Flakes.”

Tony Bennett sings “Just in Time” by Jule Styne, “I Wish I Were In Love Again” by Richard Rodgers, “‘S Wonderful” by George Gershwin, and “For Once In My Life” written by Ron Miller and Orlando Murden. Bennett issues call to United Way volunteers to call, dedicates “For Once” to the telethon.

Lewis says Bennett will be back, then introduces Ed McMahon who talks about dance marathons happening around the country to raise money for MDA.

Pre-recorded segment about Syracuse’s dance marathon.

Representatives from Syracuse University join Lewis on stage to present check on behalf of Syracuse’s Greek Council for $43,532.62. Lewis talks of his admiration of young people raising money for MDA.

Joey Heatherton performs “If” by Bread, “Please Don’t Talk About Me When I’m Gone” made popular by Dean Martin.

McMahon introduces John and Terry Thompson from 7/11 stores, who join Lewis on stage to present a check for $269,000.

Mickey Rooney banters with Lewis on stage about marriage and divorce, then praises Lewis’s philanthropy for MDA and encourages audiences to call. Rooney introduces his son briefly on stage before leaving.

Lewis vamps for 1 minute until the station break by talking about Rooney’s marriages with McMahon.

Lewis introduces the first station break by explaining that it is an opportunity for local Love Network stations to introduce themselves and their local programming. Producer made an
<table>
<thead>
<tr>
<th>Time</th>
<th>Duration</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:57pm</td>
<td>57 minutes</td>
<td>Band plays out to the station break and McMahon reads an outro.</td>
</tr>
<tr>
<td>8:58pm</td>
<td>58 minutes</td>
<td>Lewis returns from the break and mentions that they always get the “bugs out” in the first hour or two of the broadcast.</td>
</tr>
<tr>
<td>8:59pm</td>
<td>59 minutes</td>
<td>Abbe Lane sings “Lover Man (Oh Where Can You Be)” made popular by Billie Holliday.</td>
</tr>
<tr>
<td>1:50am</td>
<td>5 hours, 50 minutes</td>
<td>Frank Sinatra sings “Stargazer” made popular by Neil Diamond and “Never Gonna Fall In Love Again.” He talks about the excitement and love behind the scenes. Sinatra presents Lewis with two checks totaling $7,000 from the Stardust Hotel and presents personal check for $5,000 on behalf of his two grandchildren.</td>
</tr>
<tr>
<td>1:58am</td>
<td>5 hours, 58 minutes</td>
<td>Sinatra asks for “his friend” to come out and this is the emotional reunion of Dean Martin and Jerry Lewis.</td>
</tr>
<tr>
<td>2:01am</td>
<td>6 hours, 1 minute</td>
<td>Martin and Sinatra sing a medley of songs including “I Can’t Give You Anything But Love, Baby,” “The Lady is a Tramp,” “I’ve Got the World On a String,” and “When You’re Smiling.”</td>
</tr>
<tr>
<td>2:10am</td>
<td>6 hours, 10 minutes</td>
<td>Martin and Sinatra leave the stage, and Lewis explains Martin is his “ex-partner.”</td>
</tr>
<tr>
<td>2:12am</td>
<td>6 hours, 12 minutes</td>
<td>President of International Association of Firefighters presents Lewis with a check for $401,640.</td>
</tr>
<tr>
<td>2:13am</td>
<td>6 hours, 13 minutes</td>
<td>MDA’s National Youth Chairman and 8 college representatives presents checks to Chad Everett from dance marathons for $10,300, $14,711, $13,000, $17,770, $14,300, $16,800, $19,800, $22,000.</td>
</tr>
<tr>
<td>2:18am</td>
<td>6 hours, 18 minutes</td>
<td>Lou Brown and the orchestra play out to a cut away, then the national broadcast breaks to local stations.</td>
</tr>
<tr>
<td>2:37am</td>
<td>6 hours, 37 minutes</td>
<td>Lewis is eating watermelon while Scatman Crothers sings.</td>
</tr>
<tr>
<td>2:38am</td>
<td>6 hours, 37 minutes</td>
<td>Dr. Leon Charish, head of medical advisory board, joins Lewis on stage. He announces that people with myasthenia gravis will be considered part of MD so they can receive support. He mentions 12 new centers, bringing total to 165 centers across the country. He mentions MDA’s sponsoring seminars and conferences and Jerry Lewis camps. He thanks audiences for their donations and mentions that Franklin Roosevelt and Jerry Lewis stand out as non-scientists for their work.</td>
</tr>
<tr>
<td>2:42am</td>
<td>6 hours, 42 minutes</td>
<td>Lewis praises Charish.</td>
</tr>
<tr>
<td>Time</td>
<td>Duration</td>
<td>Event Description</td>
</tr>
<tr>
<td>--------</td>
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<td>--------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>2:44am</td>
<td>6 hours, 44 minutes</td>
<td>Anna Maria Alberghetti sings an Italian opera song.</td>
</tr>
<tr>
<td>2:47am</td>
<td>6 hours, 47 minutes</td>
<td>Dr. Carl Pearson joins Lewis on stage to discuss the new Lewis Institute at UCLA with footage from the ground breaking.</td>
</tr>
<tr>
<td>2:52am</td>
<td>6 hours, 52 minutes</td>
<td>Chad Everett introduces two college representatives from McDonald’s who present Lewis checks for a running total of $318,095.</td>
</tr>
<tr>
<td>2:54am</td>
<td>6 hours, 54 minutes</td>
<td>Representatives of Reynolds Metal Company present Lewis with a check.</td>
</tr>
<tr>
<td>2:55am</td>
<td>6 hours, 55 minutes</td>
<td>Lainie Kazan sings “The Man That Got Away” popularized by Judy Garland.</td>
</tr>
<tr>
<td>3:01am</td>
<td>7 hours, 1 minute</td>
<td>Kirk Douglas appears in a pre-recorded segment (VTR) talking about the summer camps for kids with MD.</td>
</tr>
<tr>
<td>3:03am</td>
<td>7 hours, 3 minutes</td>
<td>A representative from Roller Rink Operators updates total contribution to $522,000.</td>
</tr>
<tr>
<td>3:05am</td>
<td>7 hours, 5 minutes</td>
<td>Freda Payne performs “The Way We Were” popularized by Barbara Streisand.</td>
</tr>
<tr>
<td>3:10am</td>
<td>7 hours, 10 minutes</td>
<td>Lewis makes two disclaimers: hard for audience members to be enthusiastic in the early morning but performers need the energy (“Any good doctor will tell you, it’s good for the system. You’ll atrophy sitting there.”) and the earlier VTR of Kirk Douglas was necessary because he couldn’t be there in person but he still took time to record the segment in a studio</td>
</tr>
<tr>
<td>3:12am</td>
<td>7 hours, 12 minutes</td>
<td>David Hartman introduces man with MD, David Bowman, and pre-recorded interview with Bowman. They discuss Bowman’s healthy family, what is best and difficult about his relationship with them. Bowman discusses what he can’t do as a father due to his disability and help from his wife.</td>
</tr>
<tr>
<td>3:18am</td>
<td>7 hours, 18 minutes</td>
<td>Back on stage, David Hartman announces that David’s brother who also has MD has died this morning.</td>
</tr>
</tbody>
</table>
| 3:19am | 7 hours, 19 minutes | Lewis explains that the telethon is designed with two principles: entertain the people and shock them. There is “no easy way” to explain that a child could go to sleep tonight with the tooth fairy and wake up tomorrow with MD. “If you do not believe in preventative medicine, as I do, then believe in nothing more than making a contribution for the sake of those who may be in the position of not helping themselves. If you believe in preventative medicine, then help us do the job that we’re trying to do so that with the will of God – God-willing, I should say – nothing happens to your children and we hope they live very happy and healthy lives and play as normal children should. And run [raising finger and shaking it], most importantly, they run, then you will have given up some money to go elsewhere to someone else to benefit. If do you indeed believe in preventative medicine, then you will be
helping yourselves indirectly. It’s bound to attack someone out there listening to me now. It’s bound to affect some child. It is a vicious, devious, pathetic kind of a killer. It strikes the most innocent people, children. And I will quote John Kennedy once more who said ‘The world’s greatest resource is children and they are our best hope for the future.’ So I am here tonight pleading with you to help me produce a better future for my children and yours.” There is great applause after the monologue.

<table>
<thead>
<tr>
<th>Time</th>
<th>Duration</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>3:22am</td>
<td>7 hours, 22 minutes</td>
<td>McMahon reads into a cutaway.</td>
</tr>
<tr>
<td>3:37am</td>
<td>7 hours, 37 minutes</td>
<td>McMahon reads back from cutaway.</td>
</tr>
<tr>
<td>3:37am</td>
<td>7 hours, 37 minutes</td>
<td>Adam Wade sings “The Hungry Years” by Neil Sedaka.</td>
</tr>
<tr>
<td>3:42am</td>
<td>7 hours, 42 minutes</td>
<td>McMahon introduces VP of Arthur Murray Inc. and two representatives who presents Lewis donations for running total of $102,175.</td>
</tr>
<tr>
<td>3:44am</td>
<td>7 hours, 44 minutes</td>
<td>President of Olympia Brewing Company shows short film of stores asking customers to recycle cans for MDA.</td>
</tr>
<tr>
<td>3:46am</td>
<td>7 hours, 46 minutes</td>
<td>Ed McMahon asks for a timpani roll. New tote board reads $4,018,146 to great applause.</td>
</tr>
<tr>
<td>3:47am</td>
<td>7 hours, 47 minutes</td>
<td>Lewis talks about the excitement of the theme song (“What The World Needs Now”) and the feeling “when the numbers are right.” He says appreciates the majority of people who donate and doubts he can reach the minority who don’t.</td>
</tr>
<tr>
<td>3:47am</td>
<td>7 hours, 47 minutes</td>
<td>Lewis begins to introduce next act, McMahon asks him to vamp while they set up and Lewis jokes about when he first found out about girls. McMahon says he hasn’t been drinking and has had one of Lewis’s malted milkshakes while Lewis holds one up to drink.</td>
</tr>
<tr>
<td>3:49am</td>
<td>7 hours, 49 minutes</td>
<td>Fabian sings “The Good Songs” by Toni Tennille.</td>
</tr>
<tr>
<td>9:00am</td>
<td>13 hours</td>
<td>Lewis thanks staff at KPRC.</td>
</tr>
<tr>
<td>9:01am</td>
<td>13 hours, 1 minute</td>
<td>Carrie McDowell, a young performer, sings “Somewhere Over the Rainbow” then sits on a stool on stage with Lewis and he directs her to get up off the stool, take steps, skip, and sit down to “call on the muscles of her body” in a healthy way. Lewis says that normal functions are “trapped in a metal cage” by MD in disabled children.</td>
</tr>
<tr>
<td>9:15am</td>
<td>13 hours, 15 minutes</td>
<td>Lewis says it’s cutaway time</td>
</tr>
<tr>
<td>9:31am</td>
<td>13 hours, 31 minutes</td>
<td>McMahon returns from cutaway.</td>
</tr>
<tr>
<td>Time</td>
<td>Duration</td>
<td>Event</td>
</tr>
<tr>
<td>-----------</td>
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<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>9:33am</td>
<td>13 hours, 33 minutes</td>
<td>McMahon tells about learning that Sinatra was planning to bring Martin to the show</td>
</tr>
<tr>
<td>9:35am</td>
<td>13 hours, 35 minutes</td>
<td>Arthur Forest (director) talks about having sent the band out to eat and recording music to cover for that, but now needing to prepare for next performer.</td>
</tr>
<tr>
<td>9:36am</td>
<td>13 hours, 36 minutes</td>
<td>Richie the Pook starts to perform “pookgrass” music but there is a glitch.</td>
</tr>
<tr>
<td>9:37am</td>
<td>13 hours, 37 minutes</td>
<td>McMahon vamps by introducing representatives from 7/11 who talk about a pinochle-a-thon raising money and read a customer-submitted poem called “Set Me Free” and update donation total to $1,829,000</td>
</tr>
<tr>
<td>9:41am</td>
<td>13 hours, 41 minutes</td>
<td>Richie the Pook performs with other costumed animals.</td>
</tr>
<tr>
<td>9:46am</td>
<td>13 hours, 46 minutes</td>
<td>MDA Youth Program representative presents checks from fundraising efforts for $15,000, $12,000, $11,600, $21,000, $17,900 (from Penn State), $25,000, and $31,000.</td>
</tr>
<tr>
<td>10:04am</td>
<td>14 hours, 4 minutes</td>
<td>Al Hampel from the ad agency that helps the telethon talks with Jerry, praises the telethon and the generosity it calls for.</td>
</tr>
<tr>
<td>10:07am</td>
<td>14 hours, 7 minutes</td>
<td>Lewis corrects an error from before that Houston made over $1 million, not $600,000 last year.</td>
</tr>
<tr>
<td>10:08am</td>
<td>14 hours, 7 minutes</td>
<td>New tote board reads $6,008,624</td>
</tr>
<tr>
<td>10:09am</td>
<td>14 hours, 9 minutes</td>
<td>Lewis says numbers are too low, there is work to do in about 7 hours remaining and in an abrasive monologue encourages people to call.</td>
</tr>
<tr>
<td>10:12am</td>
<td>14 hours, 12 minutes</td>
<td>Lewis asks for a bucket to get donations from the audience members and wanders through the audience demanding money.</td>
</tr>
<tr>
<td>10:16am</td>
<td>14 hours, 11 minutes</td>
<td>Lewis and McMahon send into the station break</td>
</tr>
<tr>
<td>10:30am</td>
<td>14 hours, 30 minutes</td>
<td>Lewis returns to the show dancing to a tune by the band. Then Lewis speeds up the band as a gag.</td>
</tr>
<tr>
<td>10:35am</td>
<td>14 hours, 35 minutes</td>
<td>McMahon introduces two college representatives from McDonald’s, who update running total to $758,025.</td>
</tr>
<tr>
<td>10:38am</td>
<td>14 hours, 38 minutes</td>
<td>Lewis conducts the orchestra to sing “Anchors Aweigh.”</td>
</tr>
<tr>
<td>10:39am</td>
<td>14 hours, 39 minutes</td>
<td>Julius La Rosa and Virginia Capers from the NYC broadcast to praise Lewis. They report on collecting short of $600,000 so far.</td>
</tr>
<tr>
<td>11:14am</td>
<td>15 hours, 14 minutes</td>
<td>Debbie Reynolds from New York sings a medley including “Singing In the Rain” and “Raindrops Keep Falling On My Head” then appeals for donations.</td>
</tr>
<tr>
<td>Time</td>
<td>Duration</td>
<td>Event Description</td>
</tr>
<tr>
<td>----------</td>
<td>----------</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>11:17am</td>
<td>15 hours, 17 minutes</td>
<td>McMahon breaks the station.</td>
</tr>
<tr>
<td>12:00pm</td>
<td>16 hours</td>
<td>Lewis and McMahon return from the break.</td>
</tr>
<tr>
<td>12:00pm</td>
<td>16 hours</td>
<td>Jan Murray from New York says he couldn’t believe seeing Dean Martin on the show and does a short comedy bit and donates $1000.</td>
</tr>
<tr>
<td>12:05pm</td>
<td>16 hours, 5 minutes</td>
<td>Lewis praises Oral Roberts University and Patty and Richard Roberts.</td>
</tr>
<tr>
<td>12:36pm</td>
<td>16 hours, 36 minutes</td>
<td>Lewis sings MDA-specific lyrics written by Marcy Butler to the tune of “Love Will Keep Us Together”</td>
</tr>
<tr>
<td>12:38pm</td>
<td>16 hours, 38 minutes</td>
<td>Vicki Sue Robinson and the Soul Train dancers perform “Turn the Beat Around”</td>
</tr>
<tr>
<td>12:45pm</td>
<td>16 hours, 45 minutes</td>
<td>Tote board reveal of $9,044,974.</td>
</tr>
<tr>
<td>12:45pm</td>
<td>16 hours, 45 minutes</td>
<td>President of Kitchens of Sara Lee presents film about the new Lewis Neuromuscular Research Center at UCLA and party thrown for kids with MD. He mentions a gift for MDA donors, a Sara Lee recipe book.</td>
</tr>
<tr>
<td>12:48pm</td>
<td>16 hours, 48 minutes</td>
<td>Lewis sings a song thanking McDonald’s.</td>
</tr>
<tr>
<td>12:50pm</td>
<td>16 hours, 50 minutes</td>
<td>Warner Lambert representative tells Lewis about the Schick marathons to “dance for those who can’t.”</td>
</tr>
<tr>
<td>12:52pm</td>
<td>15 hours, 52 minutes</td>
<td>Yousuf Karsh, official photographer of MDA poster children, tells Lewis about the 5 people he photographed this year and unveils each of them.</td>
</tr>
<tr>
<td>1:29pm</td>
<td>17 hours, 29 minutes</td>
<td>Dr. Michael DeBakey from Baylor tells Lewis about his MDA-sponsored facility and introduces a short film about the Baylor facility.</td>
</tr>
<tr>
<td>1:33pm</td>
<td>17 hours, 33 minutes</td>
<td>Florida Jewish Community Services present Lewis with check for $130,000.</td>
</tr>
<tr>
<td>1:35pm</td>
<td>17 hours, 35 minutes</td>
<td>McMahon introduces a bizarre short segment (about “a special family” that we were already introduced to) about a clown/mime family (Lewis as father) at Christmas time. The film is silent but set to music and includes Lewis’s hallmark physical comedy. The couple in the film has a child who appears to have a disability (perhaps the reason they are sad clowns) and they give him a gift, stand away, and when they look back, an empty brace is on the floor. The segment resembles <em>The Day the Clown Cried</em>, one of Lewis’s most controversial films.</td>
</tr>
<tr>
<td>1:43pm</td>
<td>17 hours, 43 minutes</td>
<td>In another segment, Lewis drives a NASCAR talking about what it was like to drive extremely fast. He thanks the STP Corp. for their help.</td>
</tr>
<tr>
<td>Time</td>
<td>Duration</td>
<td>Event Description</td>
</tr>
<tr>
<td>-------</td>
<td>-----------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1:44pm</td>
<td>17 hours, 44 minutes</td>
<td>A representative from Hickory Farms presents Lewis a check for $108,385.60 and donates $5,000 personally.</td>
</tr>
<tr>
<td>1:45pm</td>
<td>17 hours, 45 minutes</td>
<td>Representatives from Rouse Company talk about a DJ in a water tower for 7 days and 7 nights broadcasting 12 hours a day and needed to raise $15,000 to get him out. They present a check for $16,000 and $400,000 and $26,000 from malls.</td>
</tr>
<tr>
<td>1:48pm</td>
<td>17 hours, 48 minutes</td>
<td>Tote board check reveals $11,058,439.</td>
</tr>
<tr>
<td>1:56pm</td>
<td>17 hours, 56 minutes</td>
<td>Representatives from 7/11 present Lewis updated total to over $2 million, Lewis gives them big hugs.</td>
</tr>
<tr>
<td>1:58pm</td>
<td>17 hours, 58 minutes</td>
<td>Representative from Columbia Beauty Salons reports on funds raised from cut-a-thons and presents check for $100,000.</td>
</tr>
<tr>
<td>2:02pm</td>
<td>18 hours, 2 minutes</td>
<td>Bobby Van performs “It’s Today” from <em>Mame</em>.</td>
</tr>
<tr>
<td>2:04pm</td>
<td>18 hours, 4 minutes</td>
<td>Representatives from Helbros Watch (official time keeper of the telethon) to introduce film about Lewis Institute in New York area.</td>
</tr>
<tr>
<td>2:10pm</td>
<td>18 hours, 10 minutes</td>
<td>Mary Tyler Moore appears via VFT to appeal for donations.</td>
</tr>
<tr>
<td>2:12pm</td>
<td>18 hours, 12 minutes</td>
<td>Bob Samson from United Airlines (a man in a wheelchair with MD) talks about Lewis asking him to talk about his own experience with MD and he recalls the first time his mother needed to pick him up when he was 9. He appeals for donations and mentions that 80 million people are watching the telethon.</td>
</tr>
<tr>
<td>2:16pm</td>
<td>18 hours, 16 minutes</td>
<td>Tote board check reveals $12,021,621 presented as gift to Samson. The broadcast breaks to local stations.</td>
</tr>
<tr>
<td>2:34pm</td>
<td>18 hours, 34 minutes</td>
<td>Lewis welcomes back the audiences and says there is a lot of work to get done in 3 hours.</td>
</tr>
<tr>
<td>2:34pm</td>
<td>18 hours, 34 minutes</td>
<td>Representatives from 7/11 present new update of $2,350,000</td>
</tr>
<tr>
<td>2:36pm</td>
<td>18 hours, 36 minutes</td>
<td>Buddy Rich performs on the drums with his band.</td>
</tr>
<tr>
<td>2:42pm</td>
<td>18 hours, 42 minutes</td>
<td>Tote board check reveals $13,186,767.</td>
</tr>
<tr>
<td>2:42pm</td>
<td>18 hours, 42 minutes</td>
<td>Buddy Rich performs “Sophisticated Lady” from new album.</td>
</tr>
<tr>
<td>2:43pm</td>
<td>18 hours, 43 minutes</td>
<td>A representative from International Association of Firefighters to update running donation total to $983,105.</td>
</tr>
<tr>
<td>2:45pm</td>
<td>18 hours, 45 minutes</td>
<td>Representative from Olympia Brewing Company updates donation total to over $260,000.</td>
</tr>
<tr>
<td>2:47pm</td>
<td>18 hours, 47 minutes</td>
<td>Lewis performs “probably the most requested thing” from the last year, MDA-specific lyrics to the tune of “Could It Be Magic” by Barry Manilow.</td>
</tr>
<tr>
<td>2:51pm</td>
<td>18 hours, 51 minutes</td>
<td>Representatives from Arthur Murray Dancers update their running donation total to over $200,000.</td>
</tr>
<tr>
<td>Time</td>
<td>Duration</td>
<td>Event/Comment</td>
</tr>
<tr>
<td>-------</td>
<td>-----------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>2:53pm</td>
<td>18 hours, 53 minutes</td>
<td>Arthur Murray Dancers from Dallas, TX perform.</td>
</tr>
<tr>
<td>3:01pm</td>
<td>19 hours, 1 minute</td>
<td>College representatives from McDonald’s update their running donation total to $1,156,302.</td>
</tr>
<tr>
<td>3:03pm</td>
<td>19 hours, 3 minutes</td>
<td>Skaters from Roller Skating Rink Operator Association represent skate-a-thon participants and update running donation total to $1,103,000.</td>
</tr>
<tr>
<td>3:05pm</td>
<td>19 hours, 5 minutes</td>
<td>Dionne Warwick performs “Then Came You.”</td>
</tr>
<tr>
<td>3:09pm</td>
<td>19 hours, 9 minutes</td>
<td>Lewis introduces Caitlyn Jenner on VTF after Olympic gold medal win talking about struggle of MD and appeals for donations.</td>
</tr>
<tr>
<td>3:11pm</td>
<td>19 hours, 11 minutes</td>
<td>Lewis reiterates that was Caitlyn Jenner, winner of the most grueling Olympic event, the decathlon.</td>
</tr>
<tr>
<td>3:11pm</td>
<td>19 hours, 11 minutes</td>
<td>Lewis plugs his upcoming touring show, <em>Hell’s Apartment</em>.</td>
</tr>
<tr>
<td>3:14pm</td>
<td>19 hours, 14 minutes</td>
<td>Tote board check reveals $15,024,734.</td>
</tr>
<tr>
<td>3:15pm</td>
<td>19 hours, 15 minutes</td>
<td>Barry Crocker performs.</td>
</tr>
<tr>
<td>3:36pm</td>
<td>19 hours, 36 minutes</td>
<td>Lewis mentions local Detroit station’s donations are up to $1,128,000. He thanks some individuals in the entertainment for their donations</td>
</tr>
<tr>
<td>3:38pm</td>
<td>19 hours, 38 minutes</td>
<td>Representatives from Caesar’s Palace present a check for $5,000 from Sinatras and Joe Louis, the boxer, presents personal check.</td>
</tr>
<tr>
<td>3:40pm</td>
<td>19 hours, 40 minutes</td>
<td>Frank Sinatra returns to perform “For Once in My Life.” Then he appeals for donations. Then he performs “Embraceable You.” Then he appeals for donation again by reflecting on recently becoming a grandfather.</td>
</tr>
<tr>
<td>3:48pm</td>
<td>19 hours, 48 minutes</td>
<td>Lewis interrupts Sinatra starting a number to check the tote board, which reveals $16,145,852.</td>
</tr>
<tr>
<td>3:49pm</td>
<td>19 hours, 49 minutes</td>
<td>Sinatra performs “Night and Day” and receives standing ovation as he leaves the stage.</td>
</tr>
<tr>
<td>3:52pm</td>
<td>19 hours, 52 minutes</td>
<td>Lewis mentions that in 40 minutes they’re going to re-run the tape of his reunion with Martin.</td>
</tr>
<tr>
<td>3:53pm</td>
<td>19 hours, 53 minutes</td>
<td>Representative from Kitchens from Sara Lee presents Lewis a check for $110,000.</td>
</tr>
<tr>
<td>3:54pm</td>
<td>19 hours, 54 minutes</td>
<td>Representative from STP Corporation praises Lewis’s nonstop devotion to MDA and presents check for $100,000.</td>
</tr>
<tr>
<td>3:58pm</td>
<td>19 hours, 58 minutes</td>
<td>Representatives from labor unions (retail clerks, stage hands, electrical workers, and actors) present checks totaling $2,875,600 and it receives a standing ovation.</td>
</tr>
<tr>
<td>4:00pm</td>
<td>20 hours</td>
<td>Lainie Kazan performs “We’ll Fly.”</td>
</tr>
<tr>
<td>Time</td>
<td>Duration</td>
<td>Event Description</td>
</tr>
<tr>
<td>----------</td>
<td>----------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>4:05pm</td>
<td>20 hours, 5 minutes</td>
<td>Bob Samson talks about working for United and presents 9 flight attendants to present a check for over $100,000. Lewis calls Samson his “oldest kid” and “tallest man in the studio” and he gets standing ovation as he leaves the stage.</td>
</tr>
<tr>
<td>4:07pm</td>
<td>20 hours, 7 minutes</td>
<td>Lewis tells Samson that he doesn’t think the audience would ever pity him, but they stood up to honor him.</td>
</tr>
<tr>
<td>4:09pm</td>
<td>20 hours, 9 minutes</td>
<td>David Hartman introduces short film of his interview with Matthew Brown, in which he asks him about being in a wheelchair and what it feels like to be on TV. Brown says he wants to grow up to be a doctor to find a cure for MD.</td>
</tr>
<tr>
<td>4:15pm</td>
<td>20 hours, 15 minutes</td>
<td>Chad Everett, crying, asks for a camera to deliver emotional appeal for donations and donates $4,000 for each of his kids.</td>
</tr>
<tr>
<td>4:16pm</td>
<td>20 hours, 16 minutes</td>
<td>Station break</td>
</tr>
<tr>
<td>4:32pm</td>
<td>20 hours, 32 minutes</td>
<td>Lewis returns from station break.</td>
</tr>
<tr>
<td>4:32pm</td>
<td>20 hours, 34 minutes</td>
<td>Tote board check reveals $18,412,662. Lewis does napkin math to figure out how much more they need to bear last year’s total (a little less than $500,000).</td>
</tr>
<tr>
<td>4:34pm</td>
<td>20 hours, 34 minutes</td>
<td>Rerun of Martin reunion.</td>
</tr>
<tr>
<td>4:37pm</td>
<td>20 hours, 37 minutes</td>
<td>Returning to live broadcast to standing ovation. Lewis explains that he has been public about strong feelings toward Martin but he helped make Lewis’s career even if he didn’t like all the choices he made.</td>
</tr>
<tr>
<td>4:39pm</td>
<td>20 hours, 39 minutes</td>
<td>Representative from Sahara Hotel (host of the telethon) present Lewis a check for $10,00 in addition to in-kind donations.</td>
</tr>
<tr>
<td>4:40pm</td>
<td>20 hours, 40 minutes</td>
<td>Representative from Brunswick Bowling Company presents a check for $360,565. Lewis falls to the floor.</td>
</tr>
<tr>
<td>4:41pm</td>
<td>20 hours, 41 minutes</td>
<td>Representative from Warner Lambert presents a check for over $100,000 and running total of $500,000.</td>
</tr>
<tr>
<td>4:42pm</td>
<td>20 hours, 42 minutes</td>
<td>Tote board check reveals more donations than last year, $19,056,544. Lewis and McMahon hug. Lewis cries.</td>
</tr>
<tr>
<td>4:43pm</td>
<td>20 hours, 43 minutes</td>
<td>Lewis moves to center stage to Igor Moiseyev, with translator, who is in Las Vegas to record Russian dance special. He exchanges pleasantries with Lewis.</td>
</tr>
<tr>
<td>4:47pm</td>
<td>20 hours, 47 minutes</td>
<td>Moiseyev’s dance troupe performs.</td>
</tr>
<tr>
<td>4:50pm</td>
<td>20 hours, 50 minutes</td>
<td>Lewis joins the dancers on stage with shiny boots to do a goofy imitation of Russian dancing.</td>
</tr>
<tr>
<td>4:51pm</td>
<td>20 hours, 51 minutes</td>
<td>Lewis, out of breath, speaks in gibberish Russian that also sounds like Yiddish.</td>
</tr>
<tr>
<td>4:55pm</td>
<td>20 hours, 55 minutes</td>
<td>Representative from Rouse Company presents Lewis a check for $502,450.</td>
</tr>
<tr>
<td>4:55pm</td>
<td>20 hours, 55 minutes</td>
<td>Representative from 7-Up updates running donation total to $442,000.</td>
</tr>
<tr>
<td>Time</td>
<td>Duration</td>
<td>Event Description</td>
</tr>
<tr>
<td>----------</td>
<td>--------------</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>4:56pm</td>
<td>20 hours, 56 minutes</td>
<td>Representatives from 7/11 update running donation total to $2,500,000.</td>
</tr>
<tr>
<td>4:57pm</td>
<td>20 hours, 57 minutes</td>
<td>McMahon tells Lewis to relax and asks for drums for tote board check revealing $10,160,994, which is a mistake, the first number dramatically scrolls through all the numbers again but lands on 1 so McMahon walks up and changes it manually to $20,160,994. Lewis cries and laughs at once and bows at the feet of McMahon.</td>
</tr>
<tr>
<td>4:59pm</td>
<td>20 hours, 59 minutes</td>
<td>Representative from International Firefighter Association updates final donation total to $1,657,096.96.</td>
</tr>
<tr>
<td>5:00pm</td>
<td>21 hours</td>
<td>Representatives from Roller Skating Rink Operators Association update running total to exceed $1,500,000.</td>
</tr>
<tr>
<td>5:01pm</td>
<td>21 hours, 1 minute</td>
<td>Lewis explains they work for 10 months to prepare this culmination of the work.</td>
</tr>
</tbody>
</table>
APPENDIX 2C: MDA, Open Your Archives!

In this op-ed piece, I urge the MDA to open its archives for public inspection. While I currently do not have plans to submit this for publication until at least the whole dissertation is complete, I include it here in order to extend the insights from the chapter proper beyond the academic vernacular, a move I see as part of my project’s overall treatment of accessibility.

What image comes to mind when you hear the word “telethon”? If you’re over 40 and grew up with a television in the U.S., there’s a good chance it will be the face of funnyman Jerry Lewis. You might call up the image of his tired figure – sweating, with his bowtie undone around his neck – as he sung his ever-maudlin version of “You’ll Never Walk Alone” at the end of his marathon television broadcasts.

“Jerry Lewis” and “telethon” are synonymous for so many because they came together each year in front of enormous audiences to raise money for the Muscular Dystrophy Association. Since almost the very birth of commercial television, the MDA has been using the telethon format to raise money for its work to fight the 40 types of muscle disease that fall under the category of MD. The telethon has become such an identifiable media format thanks to MDA’s pioneering work that the very word “telethon” activates pangs of nostalgia for Americans over a certain age. In 1977, the MDA Labor Day Telethon was more widely watched than the Super Bowl. And the year before had even more viewers.

But if you were to try to track down these broadcasts, you would have a great deal of trouble in finding them. The same organization that helped establish the telethon format now wants to hide it from you. The MDA guards its historical telethon footage like a teenager guards a journal. This is an unacceptable tactic from an organization that made disability a major topic of public discourse in the last few decades. Keeping
telethon footage from the public that it spoke to runs counter to the very democratic
dialogic ideals the organization continues to pays lip service to.

Since the spring of 2015, I have been studying the history of the telethon as part
of my dissertation research at the University of Pennsylvania. As historians know, finding
evidence for the question you’re after is a large part of the craft of research and it requires
creativity and cleverness. What you hope is that you can locate some evidence in places
where you expect, which leads you to find evidence in places you didn’t expect. You
hope your archival trail reveals itself as you start down the path.

Something quite different happened for me.

I found some telethon footage in large media archives. At the Paley Center for
Media in New York City, I was able to watch some early telethon clips, including the
announcement for the world’s very first telethon (which was, in fact, staged by the
Damon Runyon Memorial Cancer Fund, not the MDA). The Library of Congress has a
few partial telethons in their moving image collection, available for public viewing. But
on the whole, there are very few places where you can watch historical footage – and
none where you can watch a full broadcast.

I had been warned by some colleagues that the MDA is not exactly friendly to
researchers, but of course I needed to try to ask for access to their archives anyway. I
wrote many, many emails, first to local chapters who I guessed might have tapes they’ve
stored from telethons past. A few were eager to help and said they would look for me.
One chapter even said they would be glad to send me some old DVDs. But then all the
email threads ran cold. Many chapters forwarded my email to the national headquarters.
I followed up with key contacts at the MDA headquarters, especially the public relations and multimedia services department. After a few weeks, almost no one would return my emails, except the Vice President of Multimedia Services. He said he couldn’t provide any footage. I asked whether there was footage at all or if they just can’t release the footage. It was the latter: “For various legal and other considerations, we’re not in a position to release the footage for such personal [sic] use.”

In many of the responses I received, I was referred to MDA’s YouTube channel, which I was told is a wealth of footage. There are indeed many videos on that channel, but any discerning eye will notice a few things about them. First, they are overwhelmingly recent, most of them from the last years of the MDA telethon in the late 2000s. Second, the smaller portion of older footage from the 70s and 80s is quite cleansed of the very features that made the telethon so popular and also so hotly contested: there are videos of Aretha Franklin, Frank Sinatra, and Merle Haggard, but almost none of the donation appeal monologues Lewis delivered over and over again, casting his “kids” as helpless and in need of repair-by-donation.

Non-MDA YouTube users have uploaded far more telethon content than MDA itself. There is a handful of telethon superfans who have uploaded hours and hours of telethon content from their own personal collection of recorded broadcasts. Almost none of this footage shows the telethon’s most controversial moments, which is perhaps one reason the MDA does not take umbrage with this breach of their copyright.

If you want just the evidence – just one entire telethon – you have to reach out to collectors. I was lucky enough to make contact with a researcher-friendly collector who sold me old telethon footage he has on DVDs. But this transaction felt oddly illicit. And
in some ways it is. When I asked the collector about how he obtained the footage, he
gave almost no information, saying he had gotten it from another collector. I can’t verify
this, and I know why. The MDA might not come after adoring fans uploading content on
YouTube, but they are likely less sympathetic toward the people who might critique and
expose the deep-rooted ableism of their programs.

The MDA has a lot to hide: an audience member only marginally acquainted with
disability politics will likely find early MDA telethons to be appalling. In *Parade*
magazine in September 1990 (just months after the passing of the landmark Americans
with Disabilities Act), Lewis penned a fictional first-person account of what it is like to
have a debilitating neuromuscular disease called “If I had Muscular Dystrophy.” He
writes, of “that steel imprisonment that long has been deemed the dystrophic child's
plight” and goes on to say “I realize my life is half, so I must learn to do things halfway. I
just have to learn to try to be good at being half a person.” Later, when pressed in a
television interview by Chris Wallace who asked in a heated exchange if his words reflect
how he really feels about disabled people, Lewis responded: “They can’t run with me
down the hall, can they? In truth, aren’t they given half? Haven’t they been left with half?
If there’s a degree of measurement, are they whole?” Lewis’s vision of disabled people as
incomplete and slow is preserved in the telethon, as foreboding music regularly plays
under the segments featuring families with disabled children.

The MDA today knows how this kind of content plays with audiences and it has
crafted a cunning set of tactics to keep these representations as close to the vest as
possible. But here is the essential point that might get overlooked in bandying the merits
of the MDA’s PR strategy: representations of disabled people, set in the context of civic participation that telethons routinely invoked, are part of a public discourse.

I contend that one of the most important things that MDA telethon accomplished was making disability a topic of public conversation in ways that few other organizations have done. As disability historian Paul Longmore has noted, early 20th century discourse about disability often treated the subject with hush. When the MDA put disability literally under the spotlight on its telethons, it helped inaugurate a widespread recognition of the world’s largest minority at a time when the political movement for disability rights also gained traction.

The telethon injected American discourse about disability with an enormous amount of images and ideas. And yet it is almost impossible to track down the original content now.

It would behoove the MDA to get out in front of these controversies instead of attempt to sweep them under the rug. Opening their archives would show an abiding and impressive commitment to their own involvement in American civic life. If they could craft a sophisticated and enlightened response to their own footage – noting how their own thinking about the independence and integrity of disabled lives has changed over the decades – would they not seem even more tactful in their public relations strategy?

The MDA has succeeded in their quest to keep controversy under wraps – and it comes at a sharp cost to an important public dialogue about disability in American society. We have very few rigorous studies of the telethon, despite how incredibly popular they were. We had almost no public conversation about the MDA’s decision to
end its telethon in May 2015, nor much about how the ALS Ice Bucket Challenge might be taking up what the MDA left off.

Even though we have had so little discussion in the larger arena of American civic life, disability representations continue to affect the millions of Americans with disabilities that are systematically shut out from social and cultural institutions. If the MDA wants to continue to contribute to these discussions, it must learn how to open itself up to critique and dialogue, the very lifeblood of the democracy within which it operates.
## APPENDIX 3A: Content Analysis Databases & Publications

A wide net was cast using the Proquest suite of publications. The following databases were used to assemble the sample sets.

| ABI/Inform Dateline & Trade & Industry | Science Database |
| Alt-PressWatch | Social Science Database |
| Art, Design & Architecture Collection | Sociology Database |
| Black newspapers | Telecommunications Database |
| ebrary e-books | Proquest Dissertations & Theses Global |
| EconLit | Proquest Historical Annual Reports |
| Entertainment Industry Magazine Archive | All Historical Newspaper databases with holdings in the period |
| ERIC, Ethnic NewsWatch | Research Library |
| Gannett Newsstand | Screen Studies Collection |
| GenderWatch | Social Science Database |
| Harper’s Bazaar Archive | Sociological Abstracts |
| Health Management Database | The Vogue Archive |
| International Bibliography of the Social Sciences | Women’s Magazine Archive |
| Linguistics and Language Behavior Abstracts | Women’s Wear Daily Archive |
| MLA International Bibliography | |
| Music & Performing Arts Collection | |
| PAIS Index | |
| Periodicals Archive Online | |
| Periodicals Index Online | |
| Philosopher’s Index | |
| Physical Education Index | |
| PRISMA Database with HAPI Index | |
| Accounting, Tax, & Banking Collection | |
| Arts & Humanities Database | |
| Business Market Research Collection | |
| Career & Technical Education Database | |
| Family Health Database | |
| Health & Medical Collection | |
| Health Management Database | |
| Linguistics Database | |
| Military Database | |
| Nursing & Allied Health Database | |
| Political Science Database | |
| Psychology Database | |
| Public Health Database | |
| Religion Database | |
| Research Library | |
The following table indicates the publication name and number of sources assembled into the **dance-athon sample**:

<table>
<thead>
<tr>
<th>Publication Name</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afro-American (1893-1988)</td>
<td>1</td>
</tr>
<tr>
<td>Armenian Reporter International (1967-1988)</td>
<td>1</td>
</tr>
<tr>
<td>Atlanta Daily World (1932-2003)</td>
<td>6</td>
</tr>
<tr>
<td>Back Stage (Archive: 1960-2000)</td>
<td>5</td>
</tr>
<tr>
<td>Bay State Banner (1965-1979)</td>
<td>6</td>
</tr>
<tr>
<td>Billboard (Archive: 1963-2000)</td>
<td>26</td>
</tr>
<tr>
<td>Boston Globe (1960-1985)</td>
<td>94</td>
</tr>
<tr>
<td>Boxoffice (Archive: 1920-2000)</td>
<td>11</td>
</tr>
<tr>
<td>Broadcasting (Archive: 1957-1993)</td>
<td>1</td>
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<tr>
<td>Chatelaine</td>
<td>2</td>
</tr>
<tr>
<td>Chicago Daily Defender</td>
<td>11</td>
</tr>
<tr>
<td>Chicago Tribune (1963-Current file)</td>
<td>125</td>
</tr>
<tr>
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APPENDIX 4A: Recruitment and Interview Protocols

Email to interview subject:

Hello—

My name is Kevin Gotkin and I’m a Ph.D. Candidate at the University of Pennsylvania. I’m currently working on a project about the history and significance of hack-a-thons, especially those that relate to accessibility and disability.

I would love to interview someone who’s been organizing the work you do, which I’ll compile with interviews from several other hack-a-thon organizers. The interview should take about 20 minutes.

Do you know of someone I could speak to? Thanks so much and looking forward to hearing from you.

_________________________________________________________________________________

Interview Protocol

Ask for consent to record and be quoted

What is your role at [event]?

How did the hack-athon get started?

How is it funded?

Do you have a sense of what attracts people to participate?

What are its goals? How do you know when it is successful?

How was it this year?

Have you noticed that disability hackathons have become more popular? Why do you think that might be?

Many kinds of events are called hackathons. What do you consider to be the key features of a hackathon?

Do you know of other disability hackathons?
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