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### Be The Hammer

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Be The Hammer

by

Jonathan Novick

Submitted in partial fulfillment  
of the requirements for the degree of  
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## Abstract

*Be The Hammer* is a short form documentary that tells the story of John Young, an accomplished triathlete with dwarfism. During the film we learn about his successes, his failures and what continues to drive him. John's experiences are complimented by my own commentary as a fellow little person. Although I am not as athletic as John, and I don't share the responsibilities of parenthood that he reflects on during the film, I speak from the perspective of someone who has gone through similar struggles.

As John recounts his journey of getting into physical fitness and the impact that it has had on him and those around him, the audience is provided with the unique perspective of a person within the disability community. John is not the token little person who is inspirational simply for running a marathon—he is a symbol for many people with disabilities because he has refused to accept limits set by others and has worked hard to achieve what he has. Ultimately, he has become a beacon for other little people and people with disabilities more generally. He affirms that we can all overcome the limits set in front of us.

## Project Description

I met John Young in July of 2015 in Central Park, right before the Achilles International Hope and Possibility Run. The run is a five-mile race that is coordinated by Achilles International, a fitness group that encourages veterans and people with disabilities to stay active through adaptive and supportive running programs. The signature Achilles five-mile race welcomes everyone with and without disabilities to run, roll or walk at their own pace.

At the time of the race I was in the middle of recovery from my second spinal decompression surgery. This surgery is a treatment for Stenosis, and it is unfortunately common during the lifespan of a little person with Achondroplasia. Achondroplasia is the most common type of dwarfism, a type of skeletal dysplasia that results in disproportionate bone growth. As a result of this disproportionate growth, Achondroplastic dwarfs have shorter arms and legs, an average size torso and a slightly larger head. Stenosis is one example of the complications that can occur as a result of this disproportionate bone growth, as the spinal cord grows at a faster rate than the vertebrae that surround it. The surgery takes a year of recovery and during this time it's recommended that you stay active but avoid bending, twisting or lifting anything over five pounds. Despite my fragile state, I was encouraged by the idea of an adaptive race. Walking five miles was the most activity I had attempted in a while.

When John and I struck up a conversation at the starting line, I quickly realized that he was an athlete. He had already run marathons and triathlons, and was aiming to become the first little person ever to run a full Iron Man triathlon.

In my weakened state during recovery, I couldn't fathom doing everything that he was doing—but it planted a seed. Running was possible for little people. I might not be able to run a full marathon, but at the very least I could get through my recovery and in a few years be at a place where I could go out for a light jog.

After that day I followed John on social media, and he was a constant presence of power and strength on my feeds. A few years later when I was finally fully recovered, I began my training. My plan was to run the Achilles Hope and Possibility race, the one John and I had met at years earlier. It was difficult to train for, and difficult to run the day of. But I did it and, more importantly, I enjoyed it.

This set me down a path of regular running as a form of exercise and extending the length of races that I signed up for. Eventually, I did the unthinkable and ran a half marathon. After the race, I reached out to John Young and told him about everything that I had been doing. I told him that he was the inspiration for all of it and he thanked me for the kind words. We kept in touch and, as I started to get to know him better, I realized how powerful his story was and wanted help amplify his message through film.

When I asked John if I could make a film about him, he said he needed to first discuss it with his wife Sue and their son Owen, who are also little people. Owen didn't mind, but Sue hesitated. She didn't know who I was, where this film was going, and how she and the rest of her family would be characterized. All of her concerns were put to rest when she was informed that I was also a little person. I only became aware of this after I arrived at their home and was setting up my equipment for the first interview. This family was trusting me with their personal experiences because they had faith that I would get the story right. I likely wouldn't exaggerate the drama of living with a disability,

or paint John as an inspirational person just because he is an athlete with a disability. I would, they hoped, tell a story of John Young the athlete in a way that the family could be proud of.

## Research Analysis

The creation of this film was a daunting challenge considering the limited scope of disability representation in film. In the history of disability depictions within the media, there are a few glaring tropes that are important to acknowledge.

First, the disability community is woefully underrepresented. Out of 773 regular characters on broadcast scripted series in the 2020-2021 season, 3.5 percent (27 characters) were written to have a disability. This is in comparison to the 13.3 percent of people within the United States that identify as having some type of disability (Townsend). While there is more representation than there has ever been, the majority of actors that play these characters do not have these disabilities. Examples include Freddie Highmore from ABC's *The Good Doctor*, who plays a doctor on the Autism Spectrum, Colton Dunn from NBC's *Superstore*, who plays a character who uses a wheelchair, and Perry Matfield, the blind lead on Fox's *In the Dark*. These are just a few of many examples when disability is put on like a costume and just as easily shed off by individuals outside of the disability community.

The casting of actors/actresses without disabilities to play characters with disabilities is problematic for a variety of reasons. In the most crass but accurate comparison, this miscasting is no different than early Shakespearean female roles only being portrayed by men or the abhorrent history of blackface. Disability should be

viewed on the same level as race, gender and other identities in that it should not be imitated while there are a number of members from the actual community who can and should play the role. It's also important to note the work being taken away from actors with disabilities. An actor with a disability is typically not eligible for the casting of able-bodied roles in stage and screen. It is therefore unfair to give the only role that is left that they are able to play, that of a person with that disability, to the able-bodied actor. In addition to all of these ethical issues, with the persistent casting of actors without disabilities for disabled roles, it sends a message that performers with these disabilities are not able to represent themselves and their stories for a larger audience (Harris).

Beyond the issues of numerical representation, there is growing awareness that in the history of disability cinema stories have tended to fall into the categories of "inspiration" or "pity." "Inspiration porn" is a term coined by Australian disability rights activist Stella Young. It refers to stories that present disability as a burden to live with. While disabilities can be challenging, inspiration porn applauds people with disabilities for simply existing. These types of representations are seen by people within the disability community as being designed to inspire people without disabilities to be happy with what they have, or to do more with what they have been given. Quick digestible pieces of inspiration porn can be seen floating around on social media, depicting people with disabilities doing average things like going to work or participating in sports. These images are typically accompanied by statements in bold capital letters that read "the only disability is a bad attitude" (Young, 3:09).

Another trope within the inspiration genre is the depiction of disability as something that needs to be overcome. Some notable examples include *The King's*

*Speech*, which highlights King George VI's triumph over a speech disability, *The Theory of Everything*, about Stephen Hawking's struggles to overcome his motor neuron disease, and *Stronger*, which highlights the recovery of Jeff Bauman who lost both of his legs during the Boston Marathon bombing. These are moving biopics, but it's unsettling to recognize that in each of these films it is the character's disability that serves as the antagonist. Audiences rarely get the opportunity to view nuanced stories of romance, celebration or self-exploration involving characters whose disabilities are a positive part of their identity (Muredda).

There are also too many films that encourage pity for people with disabilities. These tell a story of a person with a disability as a helpless member of society who should be sympathized for or pitied (Kim). Like inspiration, pity reduces disability to a plot device for drama rather than being portrayed as something more complex or substantive.

In documentary film, some of the earliest representations of people with disabilities were steeped in pity. In Fredrick Wiseman's 1967 documentary *Titicut Follies*, the audience is provided with a view of life inside the Massachusetts Correctional Institution, Bridgewater. In Bridgewater, individuals with disabilities were being held against their will, not cared for and mistreated by staff. In Geraldo Rivera's 1972 scandalous exposé *Willowbrook: The Last Great Disgrace*, cruel and inhuman treatment was being given to people with disabilities at Willowbrook State School in Staten Island, New York.

In both of these films, the conditions were presented as inhumane and needing to be remedied. In the instance of Willowbrook, the film directly resulted in the institution



being shut down. While the work had a positive impact on the living conditions for people with disabilities, it unfortunately reinforced the idea of pity. In his criticism of *Titicut Follies*, Roger Ebert wrote, “It is hard to imagine more humiliating and pathetic scenes, and perhaps they should not be shown for profit or offered to the public” (Ebert). These individuals were seen as not able to take care of themselves or to stand up for themselves, and ultimately as needing to be rescued. At the time, this sentiment was already being broadcast in twenty-four hour blocks on television by Jerry Lewis.

From 1966 to 2010, comedian, actor, singer and filmmaker Jerry Lewis hosted the Muscular Dystrophy Association Labor Day telethon. Over the years this telethon raised millions of dollars for the Muscular Dystrophy Association (MDA), which proudly touted that it was “Saving Jerry’s Kids.” This appeared to be for a good cause, but the production was permeated with the ableist ideology that these people needed “saving.” Hour by hour the telethon showed actual children with muscular dystrophy, accompanied by observations that they needed help and to be cured. This perpetual display reinforced the pity trope and planted the idea in the minds of many that people with Muscular Dystrophy and others within the disability community will have no hope or value in their lives until a cure is discovered.

In the proceeding paragraphs, I have touched on the importance of on-screen representation of people with disabilities and the unfortunate dichotomy of inspiration/pity that is rampant within disability storytelling. All of the films mentioned were created by filmmakers without disabilities. When filmmakers with disabilities have a chance to represent the community, their depictions are very different. When provided with the opportunity, many filmmakers with disabilities focus on injustices against the disability

community and work to reframe how society sees and thinks about people with disabilities.

*The Kids Are All Right* is a half-hour documentary about a renegade “Jerry’s Kid” named Mike Ervin. Ervin was an MDA poster child in the 1960s. Today, and in the film, Mike is an outspoken disability rights activist who challenges the MDA telethon’s representation of people with disabilities through his activist group Jerry’s Orphans. The goal of *The Kids Are All Right* is to raise consciousness about the effects of pity, to empower people with disabilities to advocate for their own rights, and to inspire activism.

*Crip Camp* is a documentary about a summer camp for people with disabilities that eventually sparked the disability rights movement. The film begins with a celebration of life for people with disabilities in a manner typically not referenced on screen with mentions of partying, sex and other mischief that typical teens in a summer camp would get into. This energy and new way of life becomes a transformative force for people in the film, showing them that the world for people with disabilities can change, and that the community can work together to make it happen. Eventually we watch these former campers fight for change and win.

Despite the underrepresentation of disability in front of and behind the camera, supportive spaces to celebrate and view this content have emerged. Film festivals like Superfest, ReelAbilities and Sprout continue to champion filmmakers, writers, actors and performers with disabilities. Some works including *Crip Camp*, *Feeling Through* and *Life Animated* have even gone on to receive Academy Award nominations, although none have won.

With an underrepresentation of disability in film, I felt excited but hesitant when starting my film. On the one hand, these are stories that need to be told, but with a scarcity of content in the field, I needed to make sure that I got it right.

### **Thesis Production Process**

By nature, John is an inspiring person. He is highly motivated, energetic and has an incredible story that highlights the triumph of the human spirit. However, the wrong lens could turn his story into another piece of inspiration porn. John is not an inspiration because he is a little person that runs—he is an inspiration because he champions the concept of overcoming limitations set by others. This is a powerful concept for a little person, as well as for any person with a disability. I felt the most appropriate way for me to capture this message was to share my story and how it intersects with John as one of many people that he has inspired. John alone is an inspiration, but by adding my voice as a filmmaker and another person with a disability, the audience gets a better picture of what it's like growing up with a disability and the impact that representation has.

Between John and I, we explore the importance of growing up with positive influences, the challenges of adolescence, and the struggle to accepting disability as a part of our identity. All of these things add context and breadth to John's actions and complexify the positivity of his image.

When I started working on this project, I was unsure of the direction it would take. I prepared for interviews with John, his wife Sue and their son Owen. I had long lists of questions prepared that touched on their relationships with one another, athletics,

dwarfism, and disability. While I only spoke to Owen for 45 minutes, my discussion with John lasted nearly three hours and sent my mind reeling in many different directions.

As I began looking through the footage, I started to pull out what was most interesting and compelling to me. John's original inspiration to start running, his family's proximity to the 2015 Boston Marathon bombing and the positive impact that he had on Owen were the themes that stood out.

During one of Owen's most vulnerable stages of development, when he realized that he was different, he looked to a father who was confident and steadfast in his goals to better himself through fitness. As a result, Owen began carrying himself differently and participating in athletics that allowed him to compete with himself and worry less about competing against others. This is a heartwarming father and son tale about shared experience, but through the lens of disability it is a highly unique case study.

Growing up with dwarfism can be unique in the sense that a dwarf can be born into a family where they are the only one of their kind. Often parents want to keep their children safe and teach them everything they need to know about the world.

Unfortunately, many parents primarily draw from their own experiences which will be different than the child's because of their disability. As a result, there could be extra limitations and restrictions set in place by parents out of concern for the child's safety, especially if the parents are not little people.

Owen was born into a family of little people just like him. Although his parents never claimed to be experts on raising children with dwarfism, through example they reinforced important concepts of independence and perseverance through physical fitness. In a home full of little people, Owen grew up seeing his parents use adaptive

equipment like step stools and grabber sticks in order to perform daily activities—not relying on others for help. Owen also grew up witnessing his father run marathons which created a sense that it's normal for little people to accomplish ambitious athletic goals. However, not everyone is provided with that perspective.

Personally, I was raised by average sized parents to be independent in everything that I did. From getting dressed to retrieving a cup from a high counter for a glass of water, I needed to learn my own way of doing things. In addition, I was signed up to participate in team sports, like baseball, with other children. However, when the other children started to hit their growth spurts, I was suddenly not allowed to play for fear that I would get hurt. This limitation created a subconscious safety net that constantly reminded me that I am different than everyone else and am more “breakable.” It wasn't until I met John many years later that this perception was shattered.

In essence, John shows that we can reprogram how a person with a disability defines what's possible and raise a new generation of young people with disabilities who have limitless potential from the start.

### **Audience and Exhibition**

Overall, I think this film positively contributes to discourse surrounding disability and how we as a society view disability. I think people with disabilities can benefit from hearing John's message and his story. John is a person with a disability who found solace in his own routines that ultimately allowed him to achieve tremendous physical

success despite expectations set out for him. For audiences with disabilities, hearing directly about John's experiences will empower them to try more things.

I believe this film is also important for audiences without disabilities. Audience members can understand the involuntary harm that can be caused by placing assumptions and restrictions on the lives of people with disabilities. Individuals can also see the value of providing people with disabilities the space to be independent and challenge themselves in the areas of daily routine and physical fitness.

For people with and without disabilities alike, John Young's story displays a tremendous triumph of the human spirit. There is so much power to be held within determination and committing yourself to a goal. In the case of John Young, it was completing a full Iron Man triathlon, but I believe the essence of his success can be easily transferred to other areas of life.

While I am thrilled at the conversations that I was able to have and record with the Young family, one of my biggest obstacles was finding visual material to accompany the interviews I filmed. Through my own challenges being a little person, I had some difficulty filming the motions of John's exercises. Not only that, but I was not around for much of the story that John tells, so I had to rely on images pulled from his personal collection and the internet. As a result, I do not have the rights to several of the images that I am using and will need to make adjustments before distribution and screenings.

Eventually I would like to share this film at the ReelAbilities Film Festival, among others, and see if it could be streamed or broadcast.

I do not have a signed release form from John, Sue or Owen. This was not because they refused to sign but because I felt uncomfortable asking, and I still do. As a

fellow little person, I feel as though I have a responsibility to work with them to create a story that we are all proud of. Because of the complications around representation mentioned above, I want to keep the conversation with the Youngs going to ensure that I am presenting John's story in a way that feels comfortable to them. However, for my own protection and to get this film to a place where it is marketable, John and his family must eventually reach a point where they trust me and sign releases.

I may be the owner of the film, but it is their story. We have a shared experience as little people and once the release is signed it feels as though I am taking sole ownership of this which feels fundamentally wrong. To make terms more agreeable for John as well as for my own ethical reasons I may adjust the release to narrow the range of uses he grants me for his image. I don't feel comfortable asking for full rights to use his image in this film and other variations. Instead, I would make adjustments to the release that specifically state when and how I am permitted to use John's image. With these restrictions, I hope to remove dark corners of uncertainty that might be looming in John's mind when he signs the release.

The overall message of John's story is a positive one that emphasizes the importance of adaptive fitness and exploring limits as a person with a disability. However, there are additional constraints that need to be acknowledged in order for the film to be fully inclusive of the disability community and all of the other underrepresented communities that intersect with it. These concepts were highlighted early on in the disability rights movement under the term "Disability Justice."

The Disability Justice movement is centered around the advocacy of disabled people of color, immigrants with disabilities, members of the LGBTQ trans and gender

non-conforming communities that have disabilities, people with disabilities who are homeless, people with disabilities who are incarcerated, and people with disabilities who have had their ancestral lands stolen, among others. This concept was initially developed by queer disabled women of color Patty Berne, Mia Mingus, and Stacy Milbern, in the San Francisco Bay Area. Disability Justice was conceived in reaction to their exclusion from the mainstream disability rights movement and disability studies discourse and activism, as well as to the ableism prevalent in activist spaces (Berne).

Through the lens of disability justice, it's important to acknowledge that not all people with disabilities have the advantages that John has. John is able to afford the equipment, time and travel required to train and participate in various races and triathlons. For people with dwarfism who are part of other marginalized groups, there may be additional challenges. Women with dwarfism, for example, may not feel comfortable running alone at night. Dwarfs who are economically disadvantaged may not have the disposable income to afford running shoes, pool memberships or the custom bike that John needed to succeed in his triathlon. It is important to acknowledge the additional barriers that some people with disabilities face.

At the end of the film, during the credits, there is an acknowledgement of some of the adaptive fitness groups that are mentioned throughout the film. These are non-profit organizations that work with people with disabilities to provide them with the space and support to exercise through running and biking. [Achilles International](#) is a global not-for-profit that works to transform the lives of people with disabilities through athletic programs and social connections. [InTandem Bike](#) works to provide tandem cycling programs to people who are blind, have low vision or cannot ride. During these credits



the film does not explicitly mention disability justice, but the references make clear there are approaches to fitness that provides community support for everyone.

*Be The Hammer* is an in depth look at the story of John Young, a little person that has run marathons, long distance triathlons and other impressive feats. In my experience as a fellow little person athlete, I set out to get to know John and what drives him on a daily basis. What I came to discover throughout this interview was the fragility of self-perception during early development as a person with a disability.

As a person with a disability I will continue to push myself and work to discover my own limitations in the areas of physical fitness but also other areas that I previously wrote off for myself due to what others have told me. As I grow older and start a family of my own, I will do my best to look out for the safety of my children while not tamping down their sense of what they are capable of.

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