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Marketing disability : navigating the ethics of nonprofit development and marketing

Peyton F. Carter
University of Richmond

Marketing Disability: Navigating the Ethics of Nonprofit Development and Marketing

by

Peyton F. Carter

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Department of Sociology and Anthropology
University of Richmond
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Advisor: Dr. Jan French

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Introduction

On a chilly October afternoon at the Richmond headquarters of a local disability-services nonprofit organization, I sat down to chat with Lisa[1], the organization's Annual Fund Director. As I sat down in her office, I leaned forward in my chair, keen to listen to any and all insights into the world of nonprofit development, my chosen field of work. Our conversation seemed to broach every topic, from staffing concerns to job responsibilities. Lisa explained that she was responsible for writing the organization's two largest fundraising appeals, as well as gathering and writing supplemental stories for additional fundraising campaigns. This was a part of development strategy I was familiar with but I asked Lisa to tell me more about the process of finding and writing these stories. She said that they often approach and interview individuals and families that benefit directly from the programs. While this strategy often works well, Lisa admitted that there are times when it has backfired. I asked for an example and she told me the story of Melissa.

Melissa had served as the intern in the development department the year prior. Her brother, Jack, had a disability and worked as part of the organization's employment program. These programs consist of a variety of opportunities for individuals with disabilities to find employment, for example by working on packaging, landscaping, or custodial teams. They serve as a source of revenue for the organization's other programs while also providing stable employment opportunities for individuals with disabilities. Melissa had worked in the department for a few months and Lisa felt they

[1] All names appearing in this paper have been changed to protect the identity of the individuals referenced.

had built a good relationship. Lisa had met Jack on several occasions and had met their father once or twice. As the planning for the annual Donor Appreciation Dinner began, the task of picking a speaker arose. The speaker for this occasion was usually an individual or family member that had been positively impacted by the organization's work. Lisa immediately thought of Melissa, Jack, and their family and suggested them to the rest of the team. The team agreed that they would make excellent speakers and that it would be nice to show how a family can engage with the organization in multiple ways – both by volunteering with the organization as an intern and by directly benefiting from the organization's programs.

Lisa set off to discuss the opportunity with Melissa. What Lisa found when she spoke to Melissa, however, was neither excitement nor appreciation. Melissa was deeply offended by Lisa's offer. She accused Lisa and the team of wanting to exploit her family. She was most perturbed by their suggestion that Jack speak about his job and the meaning it holds for him. Melissa and her family felt to participate in the dinner would be to exploit Jack's disability in order to inflate the ego of the organization's donors, and thus declined to participate. Lisa was dumbfounded. She had thought Melissa's family would certainly take advantage of the opportunity to share their story and the impact of the organization on their lives, but she found the opposite to be true. Lisa said the previous workplace-friendship they had shared had been altered completely and never returned to what it was before Lisa asked Melissa and her family to speak at the dinner.

In her recounting of this interaction, Lisa reveals a paradox that is inherent to the field of nonprofit development. Organizations, like the one with which I spent six months

working, are forced to market themselves to donors and potential clients in order to raise funds to continue their work and uphold their missions. In doing so, they share their work and the recipients of their aid with a wide audience. However, the constituencies with which these organizations work are often marginalized in some ways – in this case, the organization supported individuals with disabilities. The staff members responsible for the creation of marketing content are often non-disabled, thus creating an unequal power balance between those being represented and those who are working on producing the representations. This inequality calls into question the methods by which these representations are produced as well as their broader implications. How, then, are nonprofit organizations to balance the need to market their mission and raise funds with the ethical precariousness of representing individuals with markedly less social or cultural capital, such as individuals with disabilities?

In this paper, I explore how nonprofit organizations arrived at their current model, which often include a heavy emphasis on the need for private donations, and the resulting need of organizations to assert their value and be competitive in the marketplace. By attending to the specific marketing practices of one disability services nonprofit, I show how the complexities of power relations and issues of representation manifest themselves in the nonprofit sector.

Neoliberal Histories

A complete consideration of the ethical precariousness created by nonprofit marketing practices must also attend to the nonprofit sector itself and how it arrived at its current model – one that resembles for-profit organization in its need for successful marketing and reliance on income from the private sector. The nonprofit sector has its roots in a neoliberalized version of the welfare state.

The welfare state initially arose as a response to liberalism's lack of connection between state and individual and its inability to resolve social issues (Sandberg 2012, 945). Through a system based on the empowering of certain professionals[2], the state is able to shape individual conduct while retaining the ability to govern at a distance. Billie Sandberg, Associate Professor of Public Administration at Portland State University, employs Donzelot's concept of the social[3] in her exploration of the welfare state. She writes, "... the social works on behalf of the welfare state to solve the problems created by liberalism through various techniques that ensure personal security while promoting social norms" (Sandberg 2012, 946). However, the social is composed of a variety of fundamentally diverse ideas, perspectives, and strategies, causing it to be inherently

[2] "Political rule [i.e., the state] would not itself set out the norms of individual conduct, but would instill and empower a variety of "professionals" who would, investing them with authority to act as experts in the devices of social rule" (Rose quoted in Sandberg 2012, 945). In the case of private nonprofit organization, the state imbues them with expertise most clearly through financial incentives such as government-sponsored grants and tax exemptions.

[3] Sandberg uses the following quote to define the social: "The set of means which allow social life to escape material pressures and politico-moral uncertainties; the entire range of methods which make the members of society relatively safe from the effects of economic fluctuations by providing a certain security – which give their existence possibilities of relations that are flexible enough, and internal stakes that are convincing enough, to avert the dislocation that divergences of interests and beliefs would entail" (Donzelot qtd. in Sandberg 2012, 946).

unstable. As Sandberg argues, “The inherent instability of the social ultimately serves to undermine the aims of the welfare state. Through the social, the welfare state proves unable to successfully reestablish the sense of solidarity that is necessary to promote the security of the marketplace” (Sandberg 2012, 948). Thus, the successful institution of a welfare state would require direct market governance by the state to ensure stability.

Direct interference in the market is a strategy that lies in fundamental opposition to neoliberal ideologies. As a result, neoliberal policymakers attempt to problematize the welfare state and re-establish government forms that shape the market by working on those circumstances surrounding it, rather than acting directly on the market itself (Sandberg 2012, 948). Foucault’s (2008) theory of framework policy (quoted in Sandberg 2012, 952) describes how neoliberal states control market trajectories without direct interference. Instead of directly regulating the market, neoliberal states “organize all the mechanisms surrounding the marketplace to ensure its smooth functioning” (Sandberg 2012, 952). Interactions between the neoliberal state and the nonprofit sector follow this same pattern.

The Tax Reform Act of 1969, signed into law by President Nixon, provided the first real set of regulations for private foundations. Designed to bring foundations under greater oversight and public accountability, the TRA of 1969 caused a noticeable shift towards the professionalization of private foundations (Frumkin 1998, 267-269). Foundations shifted their focus inward, redesigning management structures, application, and decision-making processes, and thus caused administrative costs to increase significantly (Frumkin 1998, 269-270). Grant-making, as a result, became more

selective, restricted, and bureaucratic.

During the last quarter of the 20th century, government increased its use of contract labor for the completion of social services at all levels – local, state, and federal. This led to the formation of more private service organizations, both nonprofit and for-profit (Hasenfeld and Garrow 2012, 303). The increase in competition for government-funded contracts forced many organizations to find alternative sources of revenue. Some turned to the institution of fees and service charges, while others focused on increasing private-sector contributions. The need for funding was further heightened during the Reagan era. Under the guise of "volunteerism" – "a belief in the power of purely private, voluntary approaches to solve the problems of poverty and distress and the feasibility of relying on private charity alone to sustain the nonprofit sector's work" (Salamon 1999, 7) – significant funding reductions were made in areas where nonprofit organizations are most active (8). The institution of the 501(c) tax exempt status, and the accompanying deduction for donations in 1986 further solidified the expected role of private-sector contributions in the funding of nonprofit organizations.

This series of framework policies forced nonprofit organizations to enter into a highly competitive and unstable market. The shift towards privatization, through competition, was theoretically intended to ensure lower prices and higher quality of service. However, these positive effects never materialized. Where previously private grants, government contracts, and government funding served as stable sources of income, the compounding changes caused nonprofit organizations to marketize themselves in order to stay afloat (10). Citizens in need of aid became regarded as

customers (Hasenfeld and Garrow 2012, 306), rights and services became subject to market trends (307), and nonprofit organizations became actors and influencers within the neoliberal marketplace (Sandberg 2012, 955).

As market actors, even though by necessity, nonprofit organizations become subject or the power relations within the marketplace. Though they are often presented in nonprofit theory as passive, supplementary organizations meant to remedy problems unaddressed by the government, nonprofits have the ability and, in fact, the necessity, to act within the marketplace, and thereby have power on and influence over market trends and social perceptions in the neoliberal state. With this power should come a greater accountability for the impact an organization has, both within its own community and on the community the organization serves.

Because of their specific purpose, however, the emergence of nonprofit organizations as market actors has created its own unique set of paradoxes and challenges, not the least of which is the issue of representation. Because of the increased need for revenue generated through private sector contributions, nonprofit organizations have felt the need to market themselves to potential donors - it is, after all, difficult to raise funds if no one knows the organization's purpose. Often, the resulting marketing technique features examples of the organization's work and the stories of individuals it has helped. However, in the case of organizations that aid individuals belonging to marginalized communities, the use of the aided individuals for marketing and development purposes is ethically precarious.

In what follows, I provide a detailed explanation of my research methods, followed by examples from my fieldwork that detail the ethical preciousness I have

described. These examples attend to the two most pressing relations I witnessed in the context of representation: relations of power and relations of care. These two relational models impact the constructed representations of the organization and its clients, thus these representations and their lived consequences also deserve attention (Han 2012, 4-5, 23). Finally, I'll end with a consideration of the organization itself and its place at the center of my analysis.

Moments of Power and Care

Methodology

This research was conducted over two distinct periods. The first occurred during a nine-week span between early June and early August of 2018 when I worked full-time as an intern in the organization's development and communications department. I was most often at the organization's headquarters between 9:00am and 5:00pm, Monday through Friday, with some variation in time or location depending on my schedule and current projects.

The second period of time I spent with the organization focused more intensely on the collection of ethnographic data. During this period, which spanned from early September to early December 2018, I remained in my position as the development and communications intern, but, because I was also taking a full course-load, I only was physically present at the organization two days per week. I would often work on projects and communicate with team members remotely, but I was in the office primarily on Wednesday afternoons and Friday mornings. During this period, I took more in-depth field notes that focused on my experiences, observations, and interactions.

I also conducted interviews with three of the organization's development employees during this time: a semi-structured formal interview with Lisa, the Annual Fund Director, in her office; a formal structured interview with Nancy, the Vice President of Development, at a café near the University of Richmond one evening, as she was attending a strategic communication seminar on campus; and a life-history interview with Chris, the Assistant Vice President of Development and Major Gift Officer, in his office.

Throughout both periods I occupied a desk in the administrative area of the organization's main location. The building also housed a variety of programs, but the administrative area was somewhat separate. My desk was one of ten in a block of cubicles that was shared by the accounting, development and communications, and human resources departments. During my preliminary time with the organization, my desk was directly outside of the office of my supervisor, the Director of Communications, and I shared a cubicle with a billing clerk. However, when I returned for the primary period of my research, my desk had been moved to make room for an additional billing clerk. My new desk was on the opposite side of the cubicle block, and I then shared a cubicle with the Administrative Assistant for the development department.

My location within the office impacted the way I experienced and interacted with the space and the people in it. Because I had an assigned desk, I had a space that I was anchored to. This solidified my belonging in the area and helped with my incorporation into the team. People knew where to find me and if I was not at my desk, I had a direct line where they could leave a voicemail. The location of my desk in the open cubicle area allowed me to freely interact with the other employees, as well as those that passed by my desk, and made it possible for me to observe the interactions between other employees as well.

Although I had the opportunity to interact with employees from various departments, the majority of my interactions were with employees in the development and communications department. There were eight department staff members in total: the Vice President of Development, the Assistant Vice President of Development, the Annual Fund Director, the Director of Communications, the Public Relations Consultant,

the Volunteer Engagement and Events Manager, the Administrative Assistant, and myself, the Intern. Working with a relatively small team allowed me the opportunity to develop relationships with each person individually. However, the team was very similar demographically. All team members were white[4], had at least a college education, and most likely belonged to the middle or upper middle class. Excluding myself, ages ranged from mid twenties to late fifties, with the vast majority of the team being over the age of forty. This homogeneous demographic was a contrast to other areas of the organization, such as the program staff and the clients themselves, who represented a greater range of education levels, socioeconomic statuses, and races.

I was assigned tasks having to do with all levels of both development and communications, and I therefore was given ample opportunity to interact with all team members. Most interactions occurred in the cubicle area or in the offices that surrounded the cubicles. Chris's office was located on the other side of the building and was the only exception to this pattern. For the majority of both periods of research, I would interact with the other department employees one or two at a time, mostly as necessary for the projects I was working on. However, we had Friday morning, bi-weekly staff meetings in which I was able to watch the whole department interact at once. My physical location in the administrative office as well as my incorporation into the team, through inclusion in events such as staff meetings, allowed me to be fully immersed in my fieldsite.

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[4] While I was attentive to the differences in race between the development team and the individuals they worked with, in the majority of interactions I observed, this dynamic was less pressing than differences in ability. Future research may provide space for a deeper consideration of the various forms inequality can take in interactions such as the ones I detail in this paper. In the instances described in this paper, all participants were white.

Relations of Power

I had stopped by Nancy's office to update her about a project on which I had been working when she asked me to read the letter she had written as part of the holiday appeal. The letter was about a 17-year-old young man with disabilities and the way in which the organization had been able to help both him and his family. Curious, I asked Nancy how she gathered the information about the young man in the letter. She told me that she had contacted his parents and asked if they would be interested in being featured in the letter. After they agreed, Nancy "sat down with his mom and said 'Tell me about Joe.'" From his mother's words, Nancy then wrote the story as it appeared in the letter and sent it back to Joe's family for approval. This system of interview, creation, and approval was used for the majority of what were called "success stories," or materials that featured the always positive experiences of one individual or family.

Applying Edward Said's (1989) and Chandra Mohanty's (1984) arguments about the politics of representation within ethnography helps to illuminate the intricacies of these interactions. By highlighting anthropology's debt to colonialism, Said's theory allows space for anthropologists to reckon with the unequal relations of power that exist within their field sites and within the scholarship they produce. He writes:

> There is an almost total absence of any reference to American imperial intervention as a factor affecting the theoretical discussion. It will be said that I have connected anthropology and empire too crudely, in too undifferentiated a way; to which I respond by asking how -and I really mean how - and when they

> were separated. I do not know when the event occurred, or if it occurred at all (Said 1989, 214)

Similar to the complex relations of power intertwined in the practice of anthropology and the creation of its scholarship, there are multifaceted relations of power at work in the interactions between Nancy, Joe, and his family and the materials produced from these interactions. As explored by Mattingly in her work with occupational therapists, there is an implied power imbalance in interactions between those with disabilities and those without disabilities. While I don't believe that the development professionals consciously consider themselves to be superior to the individuals they interview, their lack of disability affords them a higher position of power. "The ways actors inhabit their bodies, their habitus, reveal how this unequal distribution of power and wealth is invisibly produced" (Mattingly 2010, 38). In this instance, Nancy is not only placed in a position of power through the status afforded to her by her body, but also through her position as a development professional acting in a professional setting. "When therapists ask patients to become partners in ordinary conversation they rarely relinquish control of interchanges. "We are not equals here," is one indelible message of the hospital setting" (75). No matter how colloquial the conversation may be, Nancy is curating content for a specific purpose and this purpose influences her actions and perspective. Additionally, Joe receives vital services on which his family depends - Nancy is employed by the organization that provides those services. Although I have no doubt that no repercussions would have been brought on to Joe's family should they have declined to participate, this inequality of power and its effects cannot be ignored.

Mohanty's (1984) theoretical work regarding the construction of the third-world woman by western, feminist anthropologists also provides a valuable tool in understanding the ethical precarities of nonprofit development. Much like the western, female anthropologist constructs the third-world woman as a perpetual victim, it is also conceivable that continually allowing individuals without disabilities to construct the representation of individuals with disabilities relegates those individuals to a status of perpetual victimhood. The need for the organization to establish and communicate its value in a competitive marketplace - both in the competition for clients and donors' funds - places the focus on what is lacking in the lives of individuals with disabilities, perpetually labeling them as always in need of intervention from the outside. While this may be the reality for some individuals with disabilities, always constructing their representation in such a light can allow the focus to be placed on an individual's disability rather than on the individual themselves.

These observations, however, are not meant to villainize the work of the development professional. The work they do in order to raise funds allows for the continuation of vital services for families like Joe's. Additionally, a critique of this nature would not be possible without the attention that was given these issue that existed long before I began my fieldwork - attention rooted in longstanding relations of care for the mission of the organization and the families it serves.

Relations of Care

The marketing and development professionals I worked with are not completely unaware of the complexities I highlighted above, though they rarely label them as such. The practice of interviewing individuals and their families, then asking them to review the materials and suggest changes indicates an awareness that goes beyond the desire to market the organization in a positive light. It is an attempt to ensure that the representation of the individual or family aligns with their own vision. I argue that this practice is a result of the relations of care I observed during my time with the organization.

Relationships between the development staff and the individuals the organization serves often go further than interviewer and interviewee. Akin to anthropologists in their fieldsites, staff members spend time with the individuals in the various programs, know them by name and interest, and make an effort to visit regularly. Sam, the department's Administrative Assistant, often visits the programs during lunch to socialize with the clients and program staff. Chris, the Assistant Vice President of Development, often takes Friday "fieldtrips," as he calls them, to visit the clients at the organization's different locations. The prevalence of habits like these demonstrates that the marketing and development team is compelled by and committed to the mission of the organization. The team's commitment to and respect for the individuals they serve goes beyond a professional duty – in many instances, it is deeply personal.

As I sat across the desk from Chris in his office, I was taken aback by his words but tried my best to hide my surprise. The outgoing and wildly personable man I had come to know over my time at the organization had suddenly adopted a much more

solemn tone. I had known previously that Chris's family had been involved with the organization for decades, but I did not fully realize the depth of Chris's connection until he told about his brother.

Chris's brother, whose name he never mentioned to me, had a severe intellectual disability that resulted in hyperactivity, caused him to be nonverbal, and significantly delayed his intellectual development. His brother's diagnosis had profound effects on Chris's family and his childhood. When Chris was fourteen years old, his mother suffered a mental breakdown brought on by the stress of caring for his brother. His brother was institutionalized shortly thereafter. Chris last visited his brother not long before his death. Traveling with one of his sons, they visited his brother at his group home in northern Virginia. Chris recalled sharing a warm, pleasant visit and fun car ride with his brother and son – his brother had always loved to ride in the car, he told me. I could see the twinkle in Chris's eye when he talked about this visit with his brother. His words expressed the same warmth as those he used to tell me stories about his children. As he recounted their visit, the warmth in Chris's voice slowly faded to sadness diluted by time and distance. Less than a year later, he told me, his brother passed away.

Nancy and the CEO of the organization at the time attended his brother's funeral. Not long after, Chris entered into discussions with the purpose of establishing a position for him at the organization. Although he has completely changed positions since then, from one in strategic business development – securing contracts for the employment programs – to one in donor relations and development – identifying, recruiting, stewarding high profile donors – Chris has always held and continues to hold his brother

as a standard for everything he and the organization does. Having started in the for-profit sector, Chris finds the work he does now rewarding in a way that is markedly different from the satisfaction he found previously. He can see the way his work allows individuals to have better days, and he understands first-hand the impact the organization has on the families they serve. “I think nonprofit work really gets in you. You can see the positive change right in front of you – it’s hard to let that go.”

Like Chris, many of the development and marketing professionals have personal connections to the organization’s mission which results in a higher level of care. However, all are continually inspired by the individuals they come to know through their work. Karen (1998) and Skär and Tamm (2001) have both shown the complex nature of caregiver-client relationships (quoted in Thelen 2015, 503). Although marketing and development professionals are further removed from clients than direct care providers, it is reasonable to assume that they also develop emotionally nuanced relationships with the individuals they come to know and whose stories they retell.

The relations of care I observed wove themselves into both policy and practice within the department. There was a heightened sense of self-awareness and often self-criticism that I attribute to the honest passion the staff had for the organization, its mission, and those it served. Without this already-established standard of care, my analysis and the discussion surrounding it would not even be possible.

Conclusion

I call attention to these complexities as they are lived and experienced to open a dialogue for the creation of more conscious development and marketing practices within the nonprofit industry. Practices that are fully conscious of the multiple layers of inequality in which they operate also acknowledge that any sort of aid work, including raising funds, cannot be separate from a multitude of political and social processes. With this acknowledgement then comes the ability to reckon with the implications of the ways in which nonprofits represent the marginalized communities they work with.

The instances recounted above allow attention to be given to specific relations within the organization and how they interact with the ethical complexities of representation in the context of development and marketing. However, it is also important to attend to the organization as a whole and its position within this analysis. Such nuanced analysis and deep consideration of the issues explored in this paper would not be possible if the organization was not already operating at a heightened level of care. The practices I witnessed during my time with the organization reflect the employees' cognizance of the larger complexities at play. Their focus on respecting the wishes, language, and perspectives set forth by the individuals and families they are representing upholds their standard of care and subtly acknowledges the ethical precariousness they must navigate. However, this precariousness can and should be considered more fully. Moving forward, it is my hope that the analysis I have presented today will spark critical consideration of current nonprofit development and marketing practices, and will eventually lead to the development of practices that grapple more completely with the ethically precarious nature of the work.

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