

**STRETCHED TO THE LIMIT:
ORGANIZATIONS FOR SHORT STATURED PEOPLE AND THE
MANAGEMENT OF STIGMA**

by

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Dedication

Dedicated to my parents for encouraging me to stand tall and proud, despite my short stature. And for having the wisdom and foresight not to pander to society's pressures to conform, and to not treat me with growth hormone.

And to those who have faced difficulties because of their stature, know that you are more than just the feet and inches your body is composed of. Never give up on the beauty of your dreams.

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List of Abbreviations

ACHON – Achondroplastic Dwarf

ADA – Americans with Disabilities Act

ADD – Attention Deficit Disorder

ADHD – Attention Deficit Hyperactivity Disorder

AH – Average Height

ASL – American Sign Language

ATM – Automatic Teller Machine

CGD – Constitutional Growth Delay

CJD – Creutzfeldt-Jakob Disease

CLL – Cosmetic Limb Lengthening

CPAP – Continuous Positive Airway Pressure

DAAA – Dwarf Athletic Association of America

DPN – Deaf President Now

DVT – Deep Vein Thrombosis

EHMs – Embodied Health Movements

ELL – Extended Limb Lengthening

FCC – Federal Communications Commission

FDA – Food and Drug Administration

GH – Growth Hormone

GHD – Growth Hormone Deficiency

HGF – Human Growth Foundation

HGH – Human Growth Hormone

HSMs – Health Social Movements

IRB – Institutional Review Board

ISS – Idiopathic Short Stature

IVF – In Vitro Fertilization

LP – Little Person or Little People

LPA – Little People of America

MAGIC – Major Aspects of Growth in Children

MRI – Magnetic Resonance Imaging

NAAFA – National Association to Advance Fat Acceptance

NIH – National Institutes of Health

NOSSA – National Organization of Short Statured Adults

PGD – Pre-implantation Genetic Diagnosis

PSA – Public Service Announcement

SIDS – Sudden Infant Death Syndrome

SPS – Short Persons Support

TLC – The Learning Channel

Abstract

Stretched to the Limit:
Organizations for Short Statured People and the Management of Stigma

by

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Chair: Renee Anspach

While there has been a significant amount of work in the sociological literature looking at how short stature has become medicalized, virtually no research has been conducted as a comparison of the organizations that deal with issues of short stature. This dissertation examines how three such organizations mobilize around issues of stigma, normalcy, and difference. The data were collected through ethnographic fieldwork and 32 in-depth interviews with organization leaders and rank-and-file members of the following organizations in the United States that are concerned with short stature: Little People of America (LPA) – an organization that seeks to celebrate the unique culture of people with dwarfism; the MAGIC Foundation – an organization for parents, providing information about enhancement technologies; and the National Organization of Short Statured Adults (NOSSA) – an organization of adult activists that seeks equal rights based on stature.

My dissertation addresses the following research questions: 1) How and why do parents and persons considered short (or different) mobilize? 2) How do these movements frame their stance toward short stature, and how does this framing reflect their ideas about difference, normalcy, and stigma? 3) How do these movements frame their stance toward technologies affecting short people? 4) What strategies and tactics do the organizations use in articulating and publicizing their stance on the Internet, in the mass media, and to the general public? 5) What causes some short statured organizations to succeed while others ultimately fail?

Utilizing previous research on social movements, I find that each organization has its own unique way of viewing short stature and subsequently how short stature should be dealt with, both within the organization and also within the general public; therefore, there is a chapter devoted to each organization. Using identity politics, assimilation, and normalization, respectively, each organization not only reacts to short stature differently, but also to the technologies that exist to mitigate the effects that short stature has, on both the individual and society-at-large. Drawing on previous work, we see how different types of social movement actors (e.g. parents, adult activists, etc.) mobilize around issues of difference, normalcy, and stigma, and whether a collective identity is created. Finally, through the dissolution of one of the three organizations during the course of this research, I directly compare the three organizations, pointing to characteristics that helped two succeed, while the other failed.

Chapter 1:

Introduction

Short stature is defined as height that is two standard deviations below the mean, or the lowest third percentile for age and sex – 5’3” and under for women and 5’7” and under for men. Using this definition, about eight million Americans are short. In the United States, short stature has been devalued and stigmatized (Moneymaker 1989), and tallness has been celebrated (Cohen 2009). Short stature has been implicated in having a negative effect on labor market outcomes (Case and Paxson 2008; Persico, Postlewaite, and Silverman 2004; Steckel 1995) and attraction (Chu and Geary 2005; Gillis and Avis 1980; Graziano, Brothen, and Berscheid 1978; Jackson and Ervin 1992), and there is an historical precedent that those of short stature have been discriminated against and mistreated (Adelson 2005a; Adelson 2005b; Koren and Negev 2005).

And yet, despite the tangible ways in which short stature matters and impacts the lives of those who are considered short, the experiences and concerns of this group of people have been trivialized. Since I began graduate school, time and again, I have been asked to defend the importance of studying short stature. Had the topic of study been race, class, or gender – topics both widely studied in the sociological literature and considered universally accepted forms of inequality – I do not think I would have been asked nearly as often to defend my choice.

Social movements around short stature face the same issue: Trivialization of their concerns on the part of the public. They face an uphill battle to persuade the public – and even their own members – that their concerns are important, and indeed, justified. By studying and giving voice to groups whose concerns often go unrecognized, makes an important contribution to our understanding of both social movements and American society. While one short statured organization (Little People of America (LPA)) has been studied on its own (Ablon 1981; Ablon 1984; Ablon 1988; Ablon 1990; Adelson 2005a; Adelson 2005b; Moneymaker 1989), providing a comparative study of these groups offers a deeper look into how these groups operate, both on their own and in relation to each other, that was previously unknown.

This dissertation provides a description and analysis of the three main groups in the United States that are concerned with issues of short stature – Little People of America (California) – an organization devoted to people with any and all types of dwarfism – the MAGIC Foundation (Illinois) – an organization for parents of children with a variety of growth disorders – and the National Organization of Short Statured Adults (New York) – an organization made up of adult activists of short stature.

Background

Two developments have been pivotal in setting the stage for the emergence of the social movements that are the subject of this study. These are first, the numerous health social movements that proliferated in the last four decades and, second, the development of new medical technologies that had the potential to affect the lives of people with short stature.

Health Social Movements

While the social movements of short statured organizations may be relatively unknown to social scientists, the existence of other health social movements is well-documented in the sociological literature. Health social movements were part of a broader politicization in the wake of the civil rights movement. Beginning in the late 1960s, the women's health movement began to challenge medical authority (see for example Anspach 2010), while the 1960's and 1970's also saw the beginning of mental health activists' fight for patient rights (see for example Anspach 1979). During the same period, the disability-rights movement – which exists today – began to fight against stigma, job and architectural discrimination (Anspach 1979; Shapiro 1994), and achieved notable success in preserving Section 504 of the Rehabilitation Act and the passage of the landmark Americans With Disabilities Act of 1990. Beginning in the 1980's, AIDS activists lobbied for further research and successfully fought for early approval of experimental drugs (Epstein 1996). More recently, we have seen environmental-health activists fight against the disproportionate exposure to toxic materials, including the environmental breast cancer movement (Brown, et al. 2004; McCormick, Brown, and Zavestoski 2003), and those with contested illnesses, such as multiple chemical sensitivity, chronic fatigue syndrome, and fibromyalgia, fight for greater recognition of previously unrecognized illnesses (Barker 2008; Conrad and Stults 2010; Dumit 2006).

Although all of the above movements have been studied, it is only recently that health social movements emerged as a distinct area of inquiry in medical sociology and social movement scholarship (Brown, et al. 2004; Banaszak-Holl, Levitsky, and Zald 2010). Because health social movements often struggle over how illness is to be defined

and treated, the study of these movements captures one of medical sociologists' traditional concerns: The socially constructed nature of medical conditions. Further, studies of health social movements focus on the range of players involved in the process of activism, including those outside of the medical realm (for example scientists), paying attention to these varying parties goes beyond those typically considered by traditional medical sociologists (Brown, et al. 2010), thereby broadening the focus of medical sociology. Studying health social movements can also contribute to research on social movements by calling attention to the importance of the body as the object of collective action. The study of health social movements has been influenced by the major theoretical fields in social movement theory: Resource mobilization, political opportunity, and frame alignment, and new social movement theory (Brown, et al. 2004; Brown, et al. 2010). As Brown, et al. (2004) suggest, however, health social movements typically include elements that cannot be fully understood using traditional social movement approaches. For example, collective action in health social movements involves emotions as well as cognitive frames, and health social movements often emerge in the absence of political opportunities (Brown, et al. 2004).

Brown, et al. (2004) outline three main types of health social movements. The first type is *health access movements*, which seek equitable access to health care and health care services. The second type is *constituency-based health movements*, which address health inequalities based on race, class, and gender. The third type – which will be focused on here – is *embodied health movements*, which address illness, disability, or disease by challenging scientific understandings.

According to Brown, et al. (2004), embodied health movements have three unique features. First, characteristic of embodied health movements is that they include the “embodied experience” of people with illness and disease. Second, they challenge prevailing medical and scientific knowledge. Third, they involve collaboration with scientists and medical professionals (Brown, et al. 2004). Each of the three organizations under study here are embodied health movements, since they are concerned with the experience of short stature, a bodily difference. However, it is important to note that movements around short stature do not share all of the features Brown, et al. (2004) describe. Members of one organization, for example, do not view themselves as ill or disabled. Members of another organization collaborate with experts but do not challenge science or medicine.

Like all social movements, in order to be successful, regardless of its stance, a collective identity needs to emerge. As Brown, et al. (2004) observe, this process involves translating personal, embodied experience into political action. The process may begin when people experience symptoms and seek professional help, only to find their experiences invalidated by health professionals. They may seek and find others (sometimes online) that share similar experiences and have ideas about the etiology or prevention of disease that directly contradict dominant medical understandings (for example multiple chemical sensitivity syndrome). Through this process, people come to develop a politicized illness identity that may become the beginning of collective action. Thus, embodied health movements begin with the experience of the individual sufferer and re-focus attention onto the group of people who come together in the hopes of creating a politicized collective illness identity.

Embodied health movements seek to create social change by challenging medical authority around common health concerns (Archibald and Crabtree 2010). They have been at the fore of questioning medicalization and contributing to the medicalization of previously unrecognized ailments (Taylor and Zald 2010). For example, the women's health movement has challenged the medicalization of pregnancy, childbirth and reproduction, while organized groups of consumers suffering from contested illnesses, such as chronic fatigue syndrome or fibromyalgia, have been a powerful force for the medicalization of these conditions.

Those involved in embodied health movements have blurred the lines between scientists and lay experts (Brown, et al. 2004; Epstein 1995; Hess 2004), and this is one way in which embodied health movements (EHMs) can also be seen as boundary movements (Brown, et al. 2004). Health social movements tend to have a paradoxical relationship with science in that groups have come to rely on medical authority while simultaneously lambasting it.

The emergence of health social movements reflects broader changes in American society in the late twentieth century. Gone are the days when patients follow medical authority unquestioningly. Instead, many patients have become increasingly informed and assertive consumers, trying to retain jurisdiction over their own bodies and their health, and often challenging medical authority in the process (Conrad 2005).

The Emergence of New Medical Technologies

Health social movements have emerged in the context of another sweeping change in science, medicine, and society, as medicine has moved out of the realm of the strictly necessary and into the realm of creating technological advances designed to make

people “better than well” (Elliott 2003). This move from treatment to enhancement has been highly contested.

Technological advancements in medicine have brought about the birth of the vaccine, X-Ray and magnetic resonance imaging (MRI) technology, and the list goes on. While technological advances have been great, the benefits of such technologies have not been universally accepted. For example, in the breast cancer movement, one of the main sources of contention has been the safety and effectiveness of mammography screening (Klawiter 2004). And in the Deaf community, there has been strong disagreement over the use of cochlear implants; viewed on the one hand as a panacea or a ticket to joining the hearing world, and on the other as a threat to the unique culture of the Deaf (Hyde and Power 2000).

One proposed “solution” to the problem of short stature has been the use of the enhancement technologies of human growth hormone (hGH) and extended limb lengthening (ELL).¹ Originally taken from the pituitary gland of human cadavers, in 1985, synthetic growth hormone was introduced and expanded the potential market for those to be treated with it – from only those with pituitary insufficiency – to children with Idiopathic Short Stature (ISS) or “short normal” children (Conrad and Potter 2004).

In 2003, FDA approval was given to treat children with ISS with hGH. This move has been a controversial one: Some say that because of the prejudice and discrimination that come with short stature, short children are entitled to enjoy the opportunities that are given to taller children, and that treatment with hGH will lessen prejudice and discrimination against short children. Despite its endorsement by parents and some professionals, however, others have argued that hGH is expensive and is often not

¹ See Appendix D for a fuller description of hGH and ELL

covered by insurance, the long-term risks are unknown, and there is no strong evidence that hGH therapy improves the psychological well-being of short children. In fact, some studies have found that hGH may actually entail psychological risks (Kelnar, et al. 1999).

A more invasive procedure to increase height is extended limb lengthening (ELL), in which bones in the legs, and sometimes arms, are broken, pins are inserted, and then the bone is expanded using a special apparatus. Extended limb lengthening has been used since 1905, but only came into greater use in the 1970s and 1980s. Like hGH, treatment with ELL is expensive and can be very risky. Height gains for both technologies tend to be modest in all but the most serious of cases.

Given the debates over the costs and risks of both procedures, and the modest height gains that both technologies offer to those who are simply short, this research will examine the stance that social movement organizations have taken in encouraging or discouraging the use of these technologies, how social movements participate in debates about their use, and how their participation reflects deeper ideas about normalcy and difference.

For some parents of short children, enhancement technologies offer a solution to the problems of prejudice and discrimination. Others, who view short stature as a positive identity may strongly oppose enhancement technologies. For those who view short stature as a unique subculture, an even greater threat is the potential use of genetic screening and pre-implantation genetic diagnosis to selectively abort “defective” fetuses. Disability rights advocates have for some time adamantly opposed the “eugenic” use of genetic screening to selectively abort “defective” fetuses. For groups such as the Deaf or

Little People, genetic screening poses a threat to their very survival as a distinct subculture.

Social movement scholars and scholars of the sociology of science have pointed to the need for the study of movement and countermovement dynamics (Epstein 2008). In this dissertation, I explore the movement for and against specific medical technologies created to mitigate the effects of short stature.

Research Questions

This research will examine how social movements concerned with short stature mobilize around notions of difference, normalcy and stigma. It asks five specific research questions. First, how and why do parents and persons considered short (or different), mobilize? Second, how do these movements frame their stance toward short stature, and how does this framing reflect their ideas about difference, normalcy, and stigma? Third, how do these movements frame their stance toward technologies affecting short people? Fourth, what strategies and tactics do the organizations use in articulating and publicizing their stance on the Internet, in the mass media and to the general public? And finally, what causes some short statured organizations to succeed while others ultimately fail?

How and why do parents and persons considered short (or different), mobilize?

This question about mobilization can be answered at both the individual and the collective levels. First, scholars have asked how individuals organize and become involved in social movements. Social movement theorists have suggested that people who do not readily belong to pre-existing social groups, specifically those with stigmatized identities, are more likely to seek out participation in social movements (Snow and McAdam 2000). There are various processes, such as “identity work”,

through which individual, personal identities become aligned with the collective identities created by social movements (Pichardo 1997; Schwalbe and Mason-Schrock 1996).

However, more is involved in social movement mobilization than individual actions: For social movements to be effective, they need to develop structure and organization, and the organization must work to heighten the saliency of a given issue (Snow and McAdam 2000). As the resource mobilization perspective has shown, individual grievances are widespread, and alone are not a sufficient cause for mobilization (Snow and Benford 1992b; Zald and McCarthy 1987). Organizations need to mobilize resources, for example; money, time, labor, infrastructure, and technology, in order to mobilize supporters and achieve change (McAdam, McCarthy, and Zald 1996; Zald and McCarthy 1987).

In order to answer this question, I interviewed both organization leaders and members of the rank-and-file. At the individual level, I asked members how they learned about the movement and became involved with the organization. I elicited and then coded for “mobilization stories” and narratives, how individual members understood and viewed their participation. At the group level, I asked organization leaders and long-time members about the history of the organization, which elicited “creation stories” about how the organization came to be and what were its goals and mission. Further, I asked long-time members about the strategies and tactics the organization uses to get financial support, win adherents, and publicize their cause (McCarthy and Zald 1977); in other words, I asked about how the organization goes about mobilizing the resources that are available to them.

How do these movements frame their stance toward short stature, and how does this framing reflect their ideas about difference, normalcy, and stigma?

Social movement scholars began using the framing perspective as a way to fill gaps left by political process and resource mobilization theories (Polletta and Jasper 2001), in an effort to understand how social movements create meaning (Benford and Snow 2000). Social movements develop collective action frames in order to gain members and constituents, win adherents, and elicit public support for their cause (Polletta and Jasper 2001).² More specifically, collective action frames create the meanings and beliefs which help to mobilize social movement organizations, offer solutions, and provide a platform from which to take action (Benford and Snow 2000). Framing can also be seen as a vehicle for identity construction, connecting individual identity with the collective one (Snow and McAdam 2000).

Benford and Snow (2000) identify what they call three “core framing tasks” (615): diagnostic framing (615), prognostic framing (616), and motivational framing (617). In utilizing framing, social movements first seek to remedy a social situation, and in doing so, seek to identify the source or cause of the problem (Benford and Snow 2000). Second, social movements identify potential solutions to their problem (Benford and Snow 2000). Third, social movements create a ‘call to arms’ for collective action (Benford and Snow 2000: 617). As Levitsky (2008) notes, the concept of collective action frames parallels the notion of grievance formation in socio-legal studies. As a necessary condition for political action, people must first interpret a problem as an

² Just as collective action frames can give social movements momentum, they can also lead to movement decline, when, for example, frames no longer resonate with constituents (Polletta and Jasper 2001).

injustice (naming), attribute blame to social forces (blaming), and seek to remedy the problem (claiming).

In order for framing to be successful, frames must resonate with members of social movements (Benford and Snow 2000). Further, collective action frames must be credible in that there is a consistency of the use of the frame within the movement, and the frame fits with historical events (Benford and Snow 2000). Framing is a dynamic process by which social movement organizations define themselves, internally, but also to other social movement organizations and the public at large (Benford and Snow 2000).

To understand each of the groups under study here, we must first examine how they frame short stature and their own situation as short people – or their collective identity. Do they view themselves (or their children) as suffering from an abnormal physical condition to be corrected medically; as a culture to be celebrated; or as “normal” adults subjected to unfair prejudice and discrimination? Each of these frames presupposes a particular kind of political action.

While the term “identity politics” did not come into vogue until the 1970s, social movement groups involved in, for example, the civil rights and women’s movements, were focused on issues of identity, culture, and meaning in ways that had not been touched upon by other perspectives (Bernstein 2005). More specifically, identity politics is one way in which stigmatized groups can frame their situation and air their grievances (Anspach 1979; Bernstein 2005; Pichardo 1997). This is especially the case with illness – for example, physical disability and mental illness (Anspach 1979) and more recently, autism (Chamak 2007) – a stigmatized personal identity, in which a collective identity has emerged (Brown, et al. 2004; Dugan and Reger 2006; Friedman and McAdam 1992;

Taylor and Zald 2010). Identity politics seeks to take a previously negative identity and turn it into a positive identity to be celebrated by emphasizing difference – even to the extent of viewing itself as a separate culture, as is the case with the Deaf (Bernstein 1997; Gamson 1995; Groch 2001; Mansbridge 2001; Shakespeare 2005). These groups seek to dismantle the negative connotations around stigmatized characteristics.

Identity politics, however, is only one way in which a group identity can emerge. Other forms of politics include assimilation and normalization. In assimilation, the outsider group seeks to emphasize sameness and attain equality with the majority (Gamson 1995). Finally, in the case of normalization, group members argue that affected people should normalize or do whatever it takes to fit into society (Wolfensberger and Tullman 1982). These groups accept societal definitions of normalcy, and their goal is to make it possible for those affected to correct their difference (see Davis 1972a; Davis 1972b).

In order to answer this question, I first utilized interviews to gain an understanding of the official stance of the organization, how organization leaders and members view short stature, how the organizational stance reflects deeper societal assumptions about stigma and normalcy, and how the organization influences societal attitudes about short statured individuals. I coded interviews to identify these deeper assumptions. I was also interested in understanding how the organization, through its activities, influences the identity of its members. I learned how membership in the organization influences members by observing at conferences, noting the kinds of activities available to members and how they participate in them. I also asked members

why they chose to participate in certain activities, and how participation has affected them.

How do these movements frame their stance toward technologies affecting short people?

How a group's members frame the "problem" of short stature, and how they diagnose the source of the problem are closely related to the kind of solutions they will advocate. If, for example, group members view short stature as an abnormal physical condition that brings disadvantage, and if they believe they should change themselves to fit in with "normals", they would be likely to seek and endorse enhancement technologies. If however, they view short stature as the basis of a separate culture to be celebrated, and their difference as a source of pride, then they would be more likely to engage in identity politics and to oppose enhancement technologies, or, at the very least, to be reluctant to embrace them. Finally, if they view short statured people as capable of full citizenship and equality, then they would be likely to disapprove of enhancement technologies. By the same token, we would expect groups who view short stature as a culture worth preserving, to be deeply concerned that genetic screening and pre-implantation genetic diagnosis will result in the selective abortion of fetuses deemed defective, such as infants with dwarfism, thereby destroying their culture.

In order to answer this question, I interviewed organization leaders about the goals and mission of the organization, and gained an understanding of the organization's position in relation to the use of enhancement technologies that they share with the public. Further, I asked about what issues the organization is concerned with and what they think the problem is, what they believe to be the cause of the problem, who they believe the key players are, what they think should be done about the problem, and how

their beliefs about human growth hormone (hGH) and extended limb lengthening (ELL) reflect their concerns. I also interviewed organization members to see what they perceive to be the goals and mission of the organization, and to see if their personal opinions regarding human growth hormone and extended limb lengthening are similar to or different from the organizational stance, and how this impacts the overall strength of the organization and its membership. I also did an analysis of organizational websites, in order to gain further insight into the positioning of the organization, and how they disseminate their stance to the public. Also, by doing ethnographic observation at the LPA and MAGIC conferences, I was able to hear others associated with the organization, such as doctors, and how they are influenced by or influence the organization's stance on enhancement technologies and genetic screening.

What strategies and tactics do the organizations use in articulating and publicizing their stance on the Internet, in the mass media, and to the general public?

The Internet has revolutionized access to health information, from medical encyclopedia entries to online support groups (Barker 2008; Conrad 2005; Conrad and Stults 2010). Social movements have used the Internet as a basis for recruitment and other movement activities, as well as a way to connect with members all over the globe (Conrad and Stults 2010). The Internet has created "virtual communities", and has provided a space for people to connect, organize, and network, who heretofore have not had an opportunity to do so (Barker 2008).

Social movement scholars have variously shown that the media is an important player in understanding movements more fully (McCarthy, Smith, and Zald 1996; Zald and McCarthy 1987; Zald 1992). Most media research, as it relates to social movements,

has been on understanding why some organizations are more successful than others in obtaining media attention (Andrews and Caren 2010). In particular, social movements can have an influence on the media, while the media can also have an influence on social movements (Andrews and Caren 2010). Hilgartner and Bosk (1988) suggest that activists and others associated with social movements compete for the scarce resource of media exposure (print space or air time), influencing which social problems find their way onto the mass media agenda, and therefore gain public attention. However, some scholars have argued that the strategies and tactics involved in winning media attention go directly against those needed to win in the political arena (Gamson 1987). Older, more established organizations are thought to gain a larger share of media attention than newer organizations (Andrews and Caren 2010). The media has a direct hand in shaping public opinion and of developing an understanding of a social movement and its issues (Andrews and Caren 2010; Gamson and Modigliani 1989; Zald 1996), but may not always be in agreement with the views of social movement organizations (Zald 1992).

In order to answer this question, I conducted a content analysis of organizational websites, both not only to see what they put forth to the public, but also to see what press they have had and how they share information with their members. I also talked to organization leaders about how they feel short stature and related issues have been portrayed in and framed by the popular press, and how this is similar to or different from organizational stances, and whether or how they deal with the media.

What causes some short statured organizations to succeed while others ultimately fail?

While it is rare and difficult to address the absence of a movement, there is some precedence in the social movement literature for such an investigation (see for example

Auyero and Swistun 2009; Goss 2006). As Goss (2006), who studied the absence of a gun control movement in the United States, so eloquently asks, “Why does something *not* happen?...It is not at all clear how one is to study, let alone explain, something that has not happened – the unobservable, the noncountable, the intangible” (20; emphasis in original). Further, “It [social science] has almost completely ignored the ‘silent’ questions: why phenomena do not start, why phenomena do not expand, why phenomena end. But studying negative outcomes is fundamental to developing a solid theoretical account of movement formation” (Goss 2006: 20).

This question would have been nearly impossible to answer if it were not for the fact that one of the three organizations under study here folded during the course of this research. But because of this occurrence, it has made the ability to look at why an organization and a movement do not succeed possible. In order to answer this question, I will also utilize the negative case method, which has been used theoretically by Emigh (1997) and empirically by Auyero and Swistun (2009), and Goss (2006), among others.

This will involve doing an in-depth comparison of how the two organizations that have survived are similar to and different from the organization that failed.³ Aside from a direct comparison of the three organizations under study here, I will utilize several blog posts that were displayed on the organization’s website before the website was shut down. These posts are the only record directly from the organization that points to reasons why the leaders of the organization felt that it could no longer continue.

³ Unfortunately, while I was able to gain access to the organization while it was active, I was unable to gain access to the organization after it folded.

Methods⁴

In order to answer the research questions outlined above, I used interviews, content analysis of archival and historical documents and popular media, and participant-observation. Multiple methods are useful in gaining a broad picture of the organizations studied. I studied Little People of America (LPA), the MAGIC Foundation, and the National Organization of Short Statured Adults (NOSSA) from the beginning of 2010 until the spring of 2012.⁵ Each of these groups represents a distinct type of politics – assimilation through normalization (MAGIC), assimilation through a quest for equal rights (NOSSA), and separation through identity politics (LPA). Further description and the history of each organization will be presented in the chapter devoted to each organization.

The first component of this research was conducting interviews with organization leaders and other associated individuals. I did face-to-face interviews with those attending the Little People of America annual conference and the MAGIC Foundation annual conference. I also conducted several phone interviews with members of LPA and MAGIC that I wanted to talk to, but was unable to connect with while attending the conferences. Because the National Organization of Short Statured Adults (NOSSA) did not have a conference or office, interviews with members and leaders of this organization

⁴ Organizations were found using the Associations Unlimited database. The search for organizations was limited in the following ways: Organizations that had specific disorders or medical conditions in the name were not used, given the limited scope and reach of such organizations. Local, regional, state, and solely international organizations were not considered – only those at the national level were included, due to the limited role of local and regional groups, financial constraints for traveling, and also given the cultural differences that exist around short stature in other countries. Finally, given the focus of this study on parents and activist groups, organizations run by or specifically for medical professionals were not included. Only organizations focusing on people with short stature and/or their families were included, although physicians may play a peripheral role in the organizations under study here.

⁵ It was the intention of the author to also study the Human Growth Foundation (HGF), however multiple attempts to contact the organization were unsuccessful. Additionally, while NOSSA is under study here, it ceased operation during this research, as I will explain in greater detail in the chapter on the organization.

all took place over the phone. Interviews were audio recorded with the respondent's permission. Names of participants have been changed except in the case of some organization leaders, whose identities it would be too difficult to conceal.⁶

The interviews followed a semi-structured format, consisting of a series of open-ended questions, followed by probes. There was a separate interview protocol for organization leaders and rank-and-file members. Interviews were between 30 and 60 minutes for members and between 60 and 120 minutes in length for leadership. The interview included questions concerning the organization's history and mission, how the group is organized, the organization's ideology, goals, and the strategies and tactics used to accomplish these goals. The interview also included questions about the respondents' participation in the organization; how long they had been a member of the organization; what positions they have held within the organization, and how their personal biography impacts their involvement in/with the organization. Organization leaders may have perspectives that differ from those of the rank-and-file, and, for this reason, I interviewed more peripheral members, as well as leaders.

I conducted a total of 32 interviews; 17 from LPA, 12 from MAGIC, and three from NOSSA. I utilized convenience sampling in talking to organization members at the conferences. In addition, I used snowball sampling – by asking group leaders and other interviewees – to suggest other individuals involved in the organization who I should speak with, including both regular members and more involved staff members of the organization. While the conferences provided a built-in sampling pool, it was much more difficult to sample people from NOSSA.

⁶ It would be nearly impossible to attempt to conceal the identities of these individuals, and as public figures, they are aware of this.

The second component of this research was a content analysis of organizational materials (Wolff 2007). Unfortunately, neither MAGIC nor NOSSA had archives. However, LPA had an extensive archive which consisted of six file boxes worth of newsletters and other publications by the organization. I read through and content analyzed all of the newsletters that the LPA historian had on file, from 1961, when the newsletter was started, until 2010. I opted to end at 2010 as that was when I began studying the organization in detail. These newsletters provided invaluable history and insight into the organization at a time when those who were involved in the organization (at that time) are no longer living. There were a few newsletters missing throughout the years, but overall, the newsletters provided a full and rich portrayal of the organization.

The third component of this research was participant-observation at organizational conferences and annual meetings. I attended two conferences in July 2011 (in California and Illinois). Attending meetings allowed me to observe first-hand the organization's activities, and provided me with access to more peripheral members of the organizations, along with organization leaders. It also gave me the opportunity to see how the organizations gained and sustained membership, and the kind of community that was created within the organizations. I took detailed field notes during the day and typed them each evening. While interviews provided what members of an organization *say*, or their stated ideology and perspectives, observations helped to tell what they actually *do*. Taken together, the two techniques yielded a more balanced and complete portrait of the organizations.

Analysis

I transcribed all of the interviews myself. All material was coded using NVivo 9 – a software program that assists in the coding, analyzing, and organizing of qualitative data. Organizational documents were converted to PDFs to be uploaded to NVivo for analysis, and field notes from the participant-observation portion of this research were typed into Microsoft Word and uploaded to NVivo. The documents, interviews, and field notes were coded and content analyzed to identify the salient themes in the data (Glaser and Strauss 1967).

I utilized a blend of inductive and deductive coding techniques, informed by grounded theory, which allowed for themes, patterns, and trends to emerge from the data (Charmaz 2006; Glaser and Strauss 1967). Initially, interviews were analyzed through open coding to discover emergent themes in the data (Charmaz 2006). A total of 158 themes emerged through this process. Each organization was given its own codes, with LPA having 64, MAGIC having 63, and NOSSA having 31. While each organization was given its own codes, there was some overlap, especially in areas where I wanted to directly compare the organizations.

Using a blend of qualitative methodologies allowed for the flexibility of researching groups that are not widely studied or understood. Using the various methods outlined here provided views from many different directions; organization leaders, members of organizations, and the researcher's own view of the organizations by becoming part of the group. This is all explicated in the data chapters of this dissertation.

Why Short Statured People?

As a qualitative sociologist, I would be remiss to write a dissertation and not discuss myself, as both a researcher and a person, in relation to the people and groups under study. It might seem easy to disregard the fact that I am a woman of short stature, but in fact, if this were not the case, I am not sure that this research could have been conducted in the first place.

Leaders of both LPA and MAGIC tried to diagnose my own short stature in light of their own definitions. At LPA, the first questions I got when I began interviewing people were either, “What kind of dwarfism do you have?” or “Are you the relative of an LP?” Despite my short stature, I definitely had a feeling of being an outsider at the conference. I felt freakishly tall – which never happens to me – and it made me wonder about how LPs viewed me. People seemed willing to speak with me, regardless of whether they viewed me as a member of the group. I do not think that this had a direct effect on my interviews, although the approach of one of the organization leaders before I attended the conference (see Chapter 2), led me to believe that had I been a tall person, I may not have been given entrée into the group in the first place.

Gaining a glimpse into LPA allowed me to contextualize my own height. On the one hand, my height was seen as an advantage because, as a short person, I was able to gain access to the group. On the other hand, my height became an advantage as I learned of the unique problems that people with dwarfism, who are of extreme short stature, face. While I have experienced some of these difficulties, my height at just below five feet made me at least a foot taller than most of the people that I interacted with at the conference.

At the LPA conference, I found myself trying to make myself appear smaller, hunching my shoulders, tucking myself in. I found myself drawn to wearing flat flip flops, as opposed to my slightly heeled sandals. How odd, to find myself doing this, when, in the world outside of LPA, I constantly strive to appear taller.

I felt at once insider and outsider. This marginality, inherent in the indistinct participant-observer role was rather uncomfortable for me. I wrote extensively about this in my field notes, and struggled with what the Little People thought of me. At points, I lamented not being a dwarf: I longed for the camaraderie and community that I saw and experienced at LPA. This once again begs the question of whether a tall person could conduct this research at all; especially considering that, at least in the case of LPA, outside interest is met with skepticism, if not fear. I am not a dwarf, but I am an LP. Even though I am not a dwarf, I felt almost immediately at home at LPA, after I got over the fact that I felt tall. We all have things in our lives that we have to rise above.

A leader from MAGIC tried to tell me that the symptoms of lupus – which I was diagnosed with in 2008 – are similar to the symptoms of growth hormone deficiency in adulthood. Was this to claim their turf and prove their expert authority over me, harmless meddling, or something else? Do leaders of organizations typically try to gain new members at any chance they get? While this encounter occurred after the tape recorder was stopped, it sticks with me as one of the defining moments of this project. It showed me that the MAGIC leadership wanted so much to fit nearly everyone with some type of health problem into their typology of growth disorders.

For example, in a November 2012 edition of MAGIC's weekly e-mail newsletter, under the Idiopathic Short Stature division, a link was provided for an article about a drug

used to treat juvenile idiopathic arthritis. The reason the article was linked is because it reported that the “drug was associated with significant catch-up growth” (Worcester 2012). Maybe this would not matter to me if I were not a person with arthritis (which I was also diagnosed with in 2008). However, this infuriated me. Surely the MAGIC leadership understands that when dealing with a child who has juvenile arthritis, height is not, nor should it be, the most serious problem. This effort to make my lupus fit into the diagnosis of growth hormone deficiency, left me skeptical about MAGIC, and made me feel that they would take their “height as a proxy for health” ideology and apply it to anyone it might fit. I suspected that they would try to sell their ideology to anyone who will listen. It also led me to appreciate the persuasive power of the rhetoric of health: Couch anything in the guise of health, and people in this country will take notice and listen; you can sell the idea to almost anyone. I, for one, remain unconvinced.

As someone who was offered the opportunity to have growth hormone treatment as a child – by a doctor who was shorter than I am now – but was ultimately not treated, made it difficult for me to see MAGIC and their ideology in a positive light. Therefore, I may look more critically at efforts to change short children, especially when the leadership of the organization told me that my own parents thought I was cute and little, and did not realize that there was anything wrong with me, but should have ultimately taken action to correct my lack of height.

It was truly difficult for me to maintain a neutral stance while I was at the MAGIC conference. It’s difficult, at least for me, to imagine that a six year old would have no qualms about receiving an injection multiple times a week, especially given the disparate number of injections that children on growth hormone receive, as compared to

their average height counterparts. I also had a difficult time accepting the relationship that MAGIC had with pharmaceutical companies, and the somewhat “secret” nature of the association. I disagree with what the leadership told me about the association, and felt that if the pharmaceutical companies truly had altruistic motives (see Chapter 3), they would have provided activities for the children, while keeping their products entirely out of the mix. There is also the fact that my personal politics are markedly different than MAGIC’s, and I do not see short stature as a problem in and of itself. I am much more of the mind that society needs to change its view of short statured people, rather than short statured people making vain attempts to change themselves to fit into society.

Unlike LPA, after attending MAGIC’s conference, I did feel its members trying to distance themselves from me, slowly icing me out. When I had several general follow-up questions, one of the leaders of the organization told me that she could not provide me with the information. Further, when I made an attempt to do a phone interview with one of the children of the founders, I was accused of using my dissertation as a platform or soapbox from which to scream to the world my insecurities about my own height. This, along with a reference to a book chapter I wrote in 2010 entitled “Why Does Growth Hurt? The Dual Role of Normalization and Stigmatization in the Experience of Growth Hormone Treatment”, led to me being labeled as “anti-growth hormone”. Since this paper was in a refereed anthology on disability studies, I am not sure how this person even gained access to it. This was honestly not something I was worried about because I did not think that anyone outside of an academic setting would be able to gain access to the publication.

From the outset, I did not feel embraced by LPA, but this changed when I was at the conference, and the more time I spent studying the organization. I felt more accepted by MAGIC, in the beginning, but in the end, I felt that the relationship turned divisive, at best. In terms of personal politics, I felt most closely related to NOSSA, both to their politics and to the fact that I seemed to fit in with NOSSA's members because of both my height (technically one inch taller than what is considered an LP), and my lack of a diagnosed condition related to my short stature. Therefore, I had strong feelings of disappointment as both a person of short stature and as a researcher when I found out that the organization was no longer in operation.

Scholars of sociology, especially those who study stigmatized groups (see for example Link and Phelan 2001), have pointed to the need for studies conducted by researchers who are members of the groups they are studying, who can directly speak to the lived experience of those under study. This research therefore contributes to the growing need for scholars to study topics that are directly related to them. At the same time, I also have attempted to honor the tradition in qualitative research of being open and honest about one's positionality in relation to their research. All of this is to say that my experience as a short woman greatly informed this research, and also allowed me access to the groups under study.

Chapter Outline/Overview

In the next chapter (Chapter 2), I will focus on Little People of America (LPA), an organization that is focused on improving the lives of people with dwarfism. I will discuss how the organization embodies separatist ideologies, and the promises and perils of identity politics as an organizing feature of group identity particular to the

organization. I will also explore the organization's equivocal view of enhancement technologies.

In chapter 3, I focus on the MAGIC Foundation, an organization mainly for parents whose children have one of several growth disorders. I examine how the organization embodies assimilation through normalization as an organizing feature of group identity, and explore the organization's positive views of enhancement technologies.

In chapter 4, I focus on the National Organization of Short Statured Adults (NOSSA), which was an organization made up of adult activists of short stature. I will look at how the organization embodied assimilation through a quest for equal rights as an organizing feature of group identity. Most importantly, I will look at NOSSA and try to make sense of the reasons for why the organization ultimately failed (which occurred during the course of this research, after I had conducted my interviews).

In chapter 5, I conclude by comparing and contrasting the three organizations under study here, in order to better understand how these groups are similar to and different from, not only each other, but also from the universe of social movement organizations that exist.

In the appendices, I provide case studies of all participants interviewed for this dissertation (Appendix A), I provide a comparison chart of the organizations, as outlined in chapter 5 (Appendix B), I provide a list of the organizations that exist for short statured people as compared to those that exist for the Deaf (Appendix C), and finally, I provide an extended discussion about the background and history of human growth hormone

(hGH) and extended limb lengthening (ELL) beyond what was provided in this chapter (Appendix D).

Chapter 2:

Little People of America (LPA)⁷

We are contradictions in packaging, for encased in our small bodies are not small minds, not small needs and desires, not small goals and pleasures, and not small appetites for a full and enriching life (Julie Rotta, as quoted in the inside cover of Ablon (1984)).

L.P.A. is an unusual organization. Its people are unusual, not because they are small, but because, for the most part, they have risen above their real and imagined handicaps to great heights (LPA Newsletter, Volume 3, Number 10, 1964: 1).

Introduction

A Little Person Can Be Anything He Wants But Tall (LPA Newsletter, Volume 4, Number 8, 1965: 4).

As I walk through the lobby, I feel completely out of place. I have gone from being pint-sized to being a giant. I tower over most of the people around me. And I cannot quite shake the feeling that once I leave here, I will never feel this way again. And I can only imagine what average height people who just so happen to be at the hotel are thinking about what they are seeing. What do they think of the world in miniature?

Scooters and wheelchairs abound, not to mention, Little People. It is only once a year that

⁷ There is a lingo that permeates LPA culture. LP is used as a stand-in for “little people” or “little person,” LPs for “little persons,” AH is used to denote “average height”, and Achon is used as shorthand for Achondroplastic. These abbreviations are used for convenience or when they make the text sound less awkward.

Little People of America hosts its annual conference, bringing people with dwarfism from across the country and world together, proving that it really is a small world after all.

And the irony was not lost on me that the 2011 national conference was held in Anaheim, California – the home of Disneyland – a place where those who are under a certain height are banned from the most exciting rides and attractions. It was against this backdrop that I began to explore all that the Little People of America organization is.

When I expressed interest in the organization, a high level member asked if I was a Little Person (LP). I indicated to this person, that no, while not a little person, my height of 4’11” makes me just one inch taller than LPA’s definition of a dwarf.⁸ This person responded in the following way: “The reason I ask about your stature is that in general LPA would not allow an outside person to attend an event if they are not connected to a little person in some way. (Too many weirdoes out there – I’m sure you can imagine.) So being 4’11” is helping you here” (Personal Communication, June 12, 2011). My height as an asset? That’s the first time that has ever happened before. And while I was shocked and slightly confused by this initial reaction, it provides terrific insight into the organization.⁹

⁸ According to the LPA website: “Membership is available to individuals with a medical diagnosis of dwarfism or form of short stature, as well as their families, grandparents, relatives, and all medical professionals. Little People of America (LPA) defines dwarfism as a medical or genetic condition that usually results in an adult height of 4’10” or shorter, among both men and women, although in some cases a person with a dwarfing condition may be slightly taller than that. The average height of an adult with dwarfism is 4’0”, but typical heights range from 2’8” to 4’8” (Little People of America, “Benefits of LPA Membership”).

⁹ Interestingly, in the 1970s and 1980s, an average height anthropologist named Joan Ablon was able to infiltrate the group, study LPA culture, and wrote two books, “Little People in America: The Social Dimensions of Dwarfism” (Ablon 1984) and “Living with Difference: Families with Dwarf Children” (Ablon 1988). Although she never describes her relationship to LPA, how she got involved in the group, if she was a Little Person or the parent of a Little Person – which it turns out she is neither – I was told that she does continue to attend the annual conference, as an honorary lifetime member of the organization. One has to wonder if there was more openness when the organization was new, it was more informal, and

As an organization, LPA is dedicated to the mission of turning short stature from a stigmatized identity into one that is celebrated and valued. However, in creating a distinct culture, little people have to define themselves over and against the average height population, creating an “us versus them” mentality. This creates fissures, not only between those of average height and little people, but between little people and other little people, as well. Those on the margins of LPA help to show that within the organization, the definition of what it means to be a dwarf is somewhat arbitrary and is socially constructed. By asserting itself via identity politics, LPA creates its own separate culture, further differentiating little people from those of average height.

This contradiction between pursuing identity politics by reinforcing, whether intentionally or unwittingly, the difference between those of short stature and those of average height, is the subject of this chapter. Drawing on my content analysis of the organization newsletter and personal observations at the LPA conference, I first describe the history and goals of LPA. Next, I draw on the content analysis of the newsletter and interviews to describe how LPA is able to create a positive identity as it relates to short stature. I then use content analysis of the newsletter and interviews to suggest that along with creating a positive identity, LPA also seeks to create a separate culture for little people. Finally, I discuss the dilemmas of identity politics and LPA’s views of enhancement technologies. As I will discuss in the conclusion, despite the fact that organization leaders and members are very much in agreement on some issues, arbitrary definitions of what it means to be a little person create fissures within the group.

people who wanted to do research on LPA were welcomed with open arms; a novelty of sorts. Unfortunately, I was unable to track her down at the conference, because I would have liked to speak with her and understand how she was able to gain access to LPA.

What is LPA?

“Short clubs” are not a new idea. In fact, the first was started in 1713 (Adelson 2005a; for a comprehensive history of dwarfism, see Adelson 2005b). But today, the most active and visible is Little People of America, a non-profit, self-help organization (Ablon 1981; Ablon 1990) “that provides support and information to people of short stature and their families” (Little People of America, “What is LPA?”). LPA was founded in 1957 by actor Billy Barty, with just 21 members, all adults, many from the entertainment industry. Some people say that Billy Barty started LPA as a publicity stunt (Adelson 2005a), but came to see a true need for the organization. The name of the organization was originally Midgets of America, but this was quickly changed to allow for a more inclusive view of membership.¹⁰

Known for providing information and resources on a variety of topics from parenting to disability rights, LPA also offers a newsletter and a national conference to its members. The organization currently has over 7,000 members in the United States and abroad, about half of which were in attendance in Anaheim at the 2011 conference. The number of members has more than doubled in the last 30 years (Ablon 1984). The first newsletter put out by the organization in 1961 noted that there were 137 present at the national conference and a total of 500 members. LPA is organized by districts and chapters; there are currently 14 districts¹¹ and 70 chapters across the United States.

¹⁰ Use of the word midget will be discussed later in this chapter.

¹¹ District 1 includes Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont with one chapter, District 2 includes New Jersey, New York, and Pennsylvania with eight chapters, District 3 includes Delaware, District of Columbia, Maryland, North Carolina, South Carolina, and Virginia with five chapters, District 4 includes Florida and Puerto Rico with five chapters, District 5 includes Indiana, Kentucky, Michigan, Ohio, and West Virginia with seven chapters, District 6 includes Illinois and Wisconsin with five chapters, District 7 includes Arkansas, Kansas, Missouri, and Oklahoma with five chapters, District 8 includes Louisiana and Texas with five chapters, District 9 includes Iowa, Minnesota, Nebraska, North Dakota, and South Dakota with three chapters, District 10 includes Arizona, Colorado,

The leadership of the organization consists of an Executive Committee, with officers, including the positions of; President, Senior Vice President, Vice President of Membership, Vice President of Public Relations, Vice President of Programs, a Treasurer, and a Secretary. There is also an Executive Board, which is made up of all of the district directors. The organization also has a Medical Advisory Board, “[T]o assist members and their physicians with medical consultations, referrals, and critical information...As a benefit of membership, LPA members are able to contact Medical Advisory Board doctors for help with diagnosis or for any medical concerns” (Little People of America, “Medical Support”). In the early days of the organization, the Medical Advisory Board consisted of doctors that had an influential and lasting impact on various fields of medicine, all focusing on dwarfism and skeletal dysplasias. Many of these doctors also attend the yearly conference, providing free medical consultations. These free consultations, which will be discussed in greater depth later in this chapter, are one of the main draws of the national conference. There are also more than 20 committees devoted to a variety of issues and topics, each of which are chaired by a member of the organization. The Parents’ Auxiliary of the LPA was a separate part of the organization, started in 1965. This offshoot was created as a place for average height (AH) parents of LP children to get support. As the organization functions today, average height parents, who will be talked about in greater depth later in this chapter, are a seamless part of the organization.

New Mexico, Utah, Wyoming, and El Paso, Texas with five chapters, District 11 includes Alaska, Idaho, Montana, Oregon, and Washington with five chapters, District 12 includes California and Nevada with six chapters, District 13 includes Alabama, Georgia, Mississippi, and Tennessee with seven chapters, and District 14 includes Hawaii with 1.

The LPA newsletter began in 1961, and has run continuously since that time. Analyzing the themes of the newsletter gives a clue as to how the organization has changed over time. When it first started, it was mainly a social column, letting members know who was getting married, having babies, and dying. Over the years, it has experienced logo and formatting changes, going from a four-page format to a 70-plus page magazine format known as “LPA Today”. Originally, the masthead was handwritten and the rest was done on a typewriter. In the early days, the newsletter had a characteristically religious bent¹² to it.¹³ It was also full of a lot of catchy, size-related phrases like, ‘THINK BIG’ and “The last five years we have grown in stature” (LPA Newsletter, Volume 1, Number 1, 1962). Convention editions of the newsletter become a yearbook of sorts, full of pictures of all of the activities that take place during the packed convention week.

In the mid-to-late 1970s, the newsletter began to have a bit more of a medical focus, having question and answer sessions with doctors, and reporting on symposiums and research being conducted on short stature. There was also an increase in advertisements for medical centers specializing in skeletal dysplasias, along with columns on the various medical complications of dwarfism. In later years, the newsletter was also full of lengthy lifestyle-type pieces that focused on the achievements of little people. Also added was a column from the perspective of an AH parent, which was introduced around the time that an AH mother of an LP child was selected as the Executive Director of the organization.

¹² And according to the newsletter’s report of conference activities, there were religious activities that occurred there, as well, including a daily invocation.

¹³ Despite the constant and early influence on the organization, it would seem that religious themes have been toned down. While I did not expressly ask interviewees about religion, only one respondent (Jack, Achondroplasia; LPA Interview #5) spoke at length about his religious practices and beliefs.

Notably, LPA is the only organization to include all types of dwarfism (there are more than 200 varieties). Most other organizations cover just one or a few types of conditions. Unlike more than 50 years ago when the organization consisted of only adults, today the organization is composed mainly of average height parents of LP children, and young adult LPs. According to one participant, “Our primary focus right now is on the kids. Identifying them early, getting the parents in, getting them over their grief and their horror and all that stuff, so that they can begin focusing on the kid, and doing what needs to be done for the kid to grow up, and do the things that they have to do” (Jon; Precocious Puberty (early puberty, which causes final adult height to be shorter than normal; U.S. National Library of Medicine A.D.A.M. Medical Encyclopedia 2013); LPA Interview #2). Given this, Adult little people serve as role models for the younger generation.

In terms of the racial and ethnic makeup of the group, the only statistics that the organization has are provided voluntarily by members. Of about the 1,400 members that provided their race, almost 1,100 were Caucasian. The remaining 300 members were a combination of races, with Hispanic, Asian, and African American being the most common, respectively. These figures seem fairly representative of the group, given that at the 2011 conference, I saw mostly Caucasian people, with a smattering of other races mixed in. The racial makeup of the organization is interesting given that dwarfism occurs equally across racial lines (Adelson 2005a). The first African American to attend a national meeting did so in 1965, and the first international member was from England and joined the organization in 1963 (LPA Newsletter, Volume 3, Numbers 1, 2, 3, and 4,

1964: 1). About half of the organization's membership volunteered their gender, and according to this, there are slightly more women than men in the organization.

The demographic characteristics of the presidents of the organization provide insight into its culture, as well. All past presidents have been Caucasian. Nearly half have been Achondroplastic dwarfs (a form of short-limbed dwarfism, and the most common form of dwarfism. Characteristics include enlarged and prominent forehead, flat nasal bridge, and prominent butt and stomach (Adelson 2005a)). Male presidents have been twice as prevalent as female presidents, and the first female President was elected to the position in 1982, coincidentally marking the 25th Anniversary of the founding of LPA.

According to the LPA website, the mission of the organization is: “[D]edicated to improving the quality of life for people with dwarfism throughout their lives while celebrating with great pride Little People’s contribution to social diversity. LPA strives to bring solutions and global awareness to the prominent issues affecting individuals of short stature and their families” (Little People of America, “Our Mission”). In its mission statement, LPA describes itself as follows:

Little People of America is a primarily all-volunteer organization for persons and families involved with the condition of dwarfism. We do not diagnose, treat, or provide genetic counseling. We are involved in peer and parent support, medical resources and referrals, scholarships, and programs that benefit the dwarfism community, while trying to promote education, community outreach, personal and family strength, and life achievements.(Little People of America 2011b; emphasis in original)

Identity Politics and the Goals of LPA

When respondents were asked their opinion of the goals and mission of LPA, most described support and coming together, and education as its main goals, along with creating awareness, both within the LP community and the broader general public, about

what it is like to be a short person in a society that values tall. Although members describe the organization's goals in terms such as "support" and "creating awareness," identity politics is implicitly woven into the organization's stated goals and missions. Among these goals are creating a positive collective identity for themselves and promulgating this identity to the general public.

Support and Coming Together: Creating a Positive Collective Identity or "Culture"

From the very beginning, LPA has been about bringing Little People together, in order to celebrate their unique contributions to the world. The organization began because "They [the founders] saw and realized the importance of a national organization to bring hope and new courage to the hundreds of lonely, unhappy and discouraged little men and women all over this country" and was considered "Friendship therapy" (LPA Newsletter, Volume 1, Number 2, 1962: 3).

One respondent described LPA as providing members with, "Emotional, social, and educational support" (Ashley; Achondroplastic Dwarf; LPA Interview #11). And yet another said, "To be a support group for people affected by dwarfism. To help society better understand that we are no different than the Average Joe, we just have trouble reaching things" (Brenda; Achondroplastic Dwarf; LPA Interview #14).

A unique characteristic of the organization is that it is, as one respondent described, "[A] cradle to grave organization" (Jon; Precocious Puberty; LPA Interview #2). This means that no matter when a person joins the organization, they become a member for the rest of their lives. This loyalty to the organization was palpable in that nearly everyone I talked to planned to stay members of LPA. Another respondent said of the organization, "[We're] one big family... When we're not together, when we're apart, we're all still, in

some way, connected” (Jack; Achondroplastic Dwarf; LPA Interview #5). This need and desire for connection is really what keeps the organization going and it is one way in which collective LP “culture” is created.

Education

According to LPA members, the goal of education has two dimensions. First is the goal to educate members, and second, is the goal to educate the outside world. One way to educate the LP community is by providing positive role models for the younger generation. In the past, when the organization was composed mostly of adults, this was not a necessity, but now that there are more and more younger Little People joining the organization, role models are of particular importance:

There have been many famous and successful little people who have acquired fame and fortune regardless of their small stature. We intend to print articles about them in the NEWSLETTER from time to time as a mental uplift and psychological inspiration. To prove that our size will not hold us back if we have the ambition and courage to work for success and recognition (LPA Newsletter, Volume 1, Number 3, 1962: 4; emphasis in original).

By providing positive role models, LPA seeks to create a sense that being a Little Person is a positive identity to be celebrated rather than a stigma to be regarded with shame.

Members also felt that LPA’s mission was to convey this positive collective identity to the public. There was also a strong sense from respondents that the role of Little People is to educate the general public and be “ambassadors”. One person went as far as to say that they often are forced to do “damage control” when well-meaning but uninformed people say ignorant or derogatory things about Little People (Teena; diagnosis unknown; LPA Interview #15). Being a member of a visible minority group means being a representative for that group, especially given the misconceptions that exist around little people specifically. According to the newsletter, “Remember, whether

you like it or not, you are on exhibit 24 hours a day. Not only to the general public, but to other members, prospective members, your friends, your associates, your children” (LPA Newsletter, Volume 4, Number 6, 1965: 2).

There are a variety of ways in which LPA is trying to provide outreach to the general public and educate average height society about the lives of people with dwarfism. LPA has planned an initiative to declare October as Dwarfism Awareness Month. This initiative is similar to other groups, such as Breast Cancer Awareness, which also happens to hold an awareness month in October. As part of the Dwarfism Awareness Month initiative, between July and September of 2012, a 15-second, silent public service announcement (PSA) was played in Times Square. According to the e-mail announcement, “This 15-second video celebrates the diversity of people with dwarfism in the United States and the contributions they make to our communities” (LPA Today Online; July 2012). Further, ‘Since the PSA airs in Times Square there is no sound with the video. Our images will tell the story of LPA, who we are and what we do’ (LPA Today Online; July 2012). Both the PSA and the commemoration of Dwarfism Awareness Month are another public avenue through which LPA is bringing attention to dwarfism and LP culture, and serves to provide outreach toward society-at-large.

As a sociologist, my own view of the goals and mission of LPA are two-fold. First, LPA seeks to create a space in which LP culture is celebrated. Second, LPA raises awareness within the general public about dwarfism. In some ways, these two goals are contradictory. How is it possible to raise public awareness when some of the people whom you are trying to educate and make aware are precisely the people that are barred from the organization? While this section focused on the stated goals and mission of LPA

– to create a positive collective identity – the following sections examine the practices through which this positive identity is created. Finally, I examine some of the tensions and contradictions of identity politics as they play out in LPA.

Little People as a Positive Identity: De-Stigmatization Strategies

The Conference

At the heart of LPA are its efforts to transform what was once a stigmatizing and negative identity into a positive collective identity or “culture,” and to celebrate this culture. Nowhere is this celebration of LP culture more apparent than in its annual conference. The first national conference was held in 1957 in Reno, Nevada.

Approximately 27 Little People attended the conference (LPA Newsletter, Volume 3, Numbers 1, 2, 3, and 4, 1964: 1). The yearly conference is an embodiment of the organization as a whole, bringing together Little People from around the country and the world. As one of my interviewees explained:

Um, it was just like a shot in the arm. You go for, you know, a few days or a week, and spend time with people that have very similar experiences, and they often do. I mean, we have an awesome week, I understand that, but we also share very common experiences. So, um, there’s strength in numbers, and you get to be around people like yourself. That’s really nice, um, it’s kind of a high, you know, being with the group. (Teena; diagnosis unknown; LPA Interview #15)

For many of the members who join LPA as adults, some of whom have never met another person with dwarfism, the experience of meeting others with dwarfism for the first time can be transforming. Mary, a social worker in her late 20s with Diastrophic Dysplasia (a condition characterized by short-limbed dwarfism, which can include cleft palate, clubfeet, and other orthopedic problems), explained that as a child, she “didn’t want anything to do with other little people” (Mary; Diastrophic Dwarf; LPA Interview #4). She decided to attend her first conference because it was being held near where she

lived and she figured she could easily leave if she did not like it. Despite her initial concerns about joining the organization, she “has been hooked ever since” she attended her first meeting (Mary; Diastrophic Dwarf; LPA Interview #4).

Mary is not alone in her reticence to attend the national convention or to get involved in LPA (Genovese 2010). Neither is the feeling of not wanting to be around other Little People. Many of the people I interviewed indicated similar feelings (see also Ablon 1984). It is common for many Little People that join the organization as adults to go to their first convention when it is held near where they live (Roloff 1999). That way, the stakes, albeit financially, are not as high, and there is an easy escape if emotions overtake the participant.

Many also indicated that they did not know any other Little People and were disarmed in seeing them for the first time. One participant with Pseudoachondroplasia (a form of short-limbed dwarfism, similar to Achondroplasia, although head growth and facial features are normal, and becomes apparent when delayed walking and abnormal gait become obvious (Adelson 2005a)) said:

I had never seen any other little people. And I walked in, and there was [*sic*] 175 people at the conference... And I like freaked out. I said, you know, “I’m not like that, I don’t look like that,” and I wanted to go home. But, my mom didn’t let me, of course. By the end of the week, and I met all these people who we found had a lot of stuff in common. So from that point on, I’ve gotten very involved with the organization. (Lana; Pseudoachondroplasia; LPA Interview #6)

One can only imagine that if Little People themselves are disarmed by seeing each other, how the general public must react upon seeing them. However, despite initial concerns, everyone I spoke with felt that once they got their feet wet in terms of participating in the organization and being around other LPs en masse, that it was overall a positive and worthwhile experience for them.

Fashion and Talent Shows

If there is one thing that is not in “short” supply at the conference, it is personality, and this is best seen in the fashion and talent shows that are held during the conference, and are two examples in which the positive identity and talents of Little People are celebrated. The fashion show is particularly striking because fashion and the runway are places that usually exclude people of short stature. It was interesting to see people dressed in the latest fashions in their size. Just as “normal” sized people, there are punk dwarfs, Goth dwarfs, and everything in between. These styles are further reflected in the cliques and groups of people that socialize at the conference. The talent show, which was more like a giant party, showcased dancers, singers, musicians, and comedians, with selections from “Grease”, the Monkees, the Beatles, and many songs that are currently popular. There were hundreds of people in attendance for this event; it was standing room only. And unlike other areas of life, where if a Little Person is seated behind an average height person, they cannot see and do not really have a choice in the matter, at this event, those of average height or on the taller end of the LPA spectrum, were relegated to the back of the theater so that everyone had an equal opportunity to enjoy the show. The talent show seemed to be a positive, upbeat celebration of Little People. Those in attendance clapped, sang along, cheered, and were full of enthusiasm and support for those taking part in these events.

Most apparent at both events is the confidence that radiates from participants, and the enthusiasm of the audience. The popularity of these events should not come as a surprise, given the legacy of dwarfs taking to the stage. The difference, however, is that

when LP is performing for LP, talents are being showcased rather than exploited by others.

Sports

Another example of this positive celebration of culture is seen at the Dwarf Athletic Association of America (DAAA) National Games. The DAAA is a separate entity from the LPA, but they arrange for their annual games to coincide with the LPA conference, and there are DAAA competitions and events throughout the week. The DAAA is a non-profit organization that was founded in 1985, providing athletic opportunities for people of short stature. The organization seeks “to develop, promote, and provide quality amateur level athletic competition opportunities for dwarf athletes in the United States” (Dwarf Athletic Association of America 2011). Further, the mission of the organization is: “[C]ommitted to providing athletic competition, guidance, support, and information to people of short stature and to their families” (Dwarf Athletic Association of America 2011).

While the outside world may see Little People as having limited abilities in terms of strength and athletic prowess, the DAAA provides opportunities for dwarf athletes to showcase their skills and talents in this arena, providing activities in which dwarf athletes can compete and succeed. Athletics, which is another realm that was once off limits to Little People, is one of the highlights of the conference. Athletes participating in DAAA frequently represent LPA and the United States in the Olympic and Paralympic games. While I was unable to attend any of the DAAA events myself (because they were offsite from the conference hotel), nearly all families with LP children that are old enough to participate, join the competitions.

Reality Show Portrayals

Fashion shows, talent shows, and athletic competitions are arenas in which Little People dramatize for *themselves* that they are attractive, talented, and athletic, fully capable of participating in activities from which they are often excluded. Another way in which Little People dramatically celebrate their unique culture – for themselves *and* the general public – is through the portrayal of dwarf families on television in reality shows and documentaries. Most people I talked to at the conference and elsewhere said that they felt that shows on The Learning Channel (TLC), such as “Little People, Big World” and “The Little Couple” – that showcase the lives of people with dwarfism – were positive appraisals of their community. The newsletter discussed this at length, highlighting the positive contributions of “Little People, Big World”:

When it was announced that Matt Roloff, former President of Little People of America, and his family were soon to appear in a...reality TV series, some LPA members expressed apprehension. While they hoped that the series would represent people with dwarfism fairly, their experiences with patronizing talk show hosts – and producers who ridiculed the “dwarf talent” they were ostensibly showcasing – had led them to wonder whether this series might be just another exploitive spectacle. Fortunately, their fears proved unfounded...Probably the greatest contribution *Little People, Big World* makes is to amend people’s sense that dwarfs are strange or alien, and hopefully, to reduce the relentless ridicule that this group encounters. (LPA Newsletter, Volume 42, Number 2, 2006: 28 and 29; emphasis in original)

One respondent said:

Um, but there’s so many tools for the future with the science. The technology. The media. Um, the publications. I mean, just getting the voice out there. I mean, they have all the shows, you know? All the different shows, you got TLC and Discovery. Things like that. It’s really I think education, letting the average size individual person understand what we go through on an every day basis. Um, and, I respect that because I see it working. (Jack, Achondroplastic Dwarf, LPA Interview #5)

And still another respondent, with Cartilage-Hair Hypoplasia (a rare form of short-limbed dwarfism, characterized by thin and light-colored hair, and hyperextendability of wrists and fingers (Adelson 2005a)), said:

Um, I think they do have, uh, the goal to reach wider audiences in the media. There are several shows that follow dwarfs. Now they're really reaching out to the general population, not only in the United States, but across the world. Um, I think little people are now becoming more acceptable. Um, I don't think there's as much mocking or pointing at. Uh, because people are seeing the shows, seeing the media, seeing the newscasts. We just happen to be short statured. We have the same mind they have, the same intelligence. We just happen to be short statured and we have a few limitations. (Adam; Cartilage-Hair Hypoplasia; LPA Interview #1)

There were a few people, however, who felt that the reality television show portrayals made them seem ridiculous. One person commented that upon seeing how "ridiculous" Amy Roloff (the mother on "Little People, Big World") looked climbing the shelves at the grocery store, that this person promptly stopped that behavior herself (Brenda, Achondroplastic Dwarf; LPA Interview #14). This reaction was in the minority, however. Far and away, the people I spoke with saw the shows in a positive light, and as a positive and accurate representation of Little People making their way in the average height world.

International Adoptions

Little People are acutely aware that the positive identity displayed at the conference is not characteristic of the wider society. In fact, there are cultures in which dwarfs remain outcasts, sometimes abandoned at birth. Thus many Little People believe they have a moral obligation to provide warm and accepting homes to children from otherwise rejecting environments. One purpose of the newsletter is to provide information about LP children available for adoption. In the early years of the

organization, potential adoptees were primarily from the United States. Today, however, the majority of children available for adoption are from other countries, specifically China, Russia, and a variety of South American countries. The newsletter was very good at appealing to people's conscience in this regard: "The child adoption service of the LPA, now have [*sic*] five children available for adoption. These children have been outcast by their parents because they were not born perfect. Ordinary people will not adopt dwarfed children. Their only hope for a home is US, in the LPA... They are only case numbers now. Maybe you will give one a name" (LPA Newsletter, Volume 1, Number 5, 1962: 1; emphasis in original).

While LPA stresses that it is not an adoption agency, there is still, even today, a focus on "[F]ind[ing] a loving home for each child with dwarfism" (Little People of America, "Adoption"), and a strong sense of responsibility toward helping those who want to adopt an LP child. It appears that most, if not all, of these adoptions are foreign rather than domestic, although there was an emphasis early on in the organization on domestic adoptions. This change in the type of adoptions, the increase in international versus domestic adoptions, is most likely a result of parents in the United States becoming more accepting of dwarf children today than they were in the 1950s, 1960s, 1970s, and even into the 1980s.

Many of the people I interviewed expressed opinions about other countries and how Little People are treated. There was a consensus that despite the obstacles that Little People face in American society, the conditions for LPs in other countries are far worse, especially relating to the use of technology, specifically limb lengthening surgery, which has been popularized in many countries abroad. One interviewee said, "So I think really,

um, using our success, Little People of America, to teach other countries how to deal with dwarfism, and how to provide for LPs, and make their society aware of what we deal with” (Mary; Diastrophic Dwarf; LPA Interview #4). LPA can be used as a model to help create similar organizations in other countries. According to Adelson (2005a), dwarfs tend to be best off in countries that have organizations specifically for Little People. Other countries, notably Russia and China, where widespread acceptance of dwarfs has been slow and organized gatherings of Little People have been almost non-existent, are the countries from which most LP children are adopted.¹⁴

In short, through their conferences, fashion shows, talent shows, and athletic competitions, LPA celebrates dwarf culture and creates and re-creates a positive collective identity for its members. Reality television shows dramatize this positive identity to Little People, as well as the outside world, and through international adoptions, Little People offer this positive identity to children from countries in which such an identity is non-existent.

Little People as a Separate Culture

Thus far, I have described how LPA celebrates LP culture. However, at the same time, LPA attempts to create, not only a positive view of Little People, but also a *separate* culture, which draws symbolic boundaries between LPs and the outside, average height world.

Membership Requirements and Suspicion of Outsiders

When asked, high level officials in the organization seemed to agree that average height people who show an interest in LPA, but have no direct connection to a Little

¹⁴ It has been a common practice in many countries other than the United States to place Little People in institutions or homes for the disabled and infirmed (Van Etten 1988).

Person, are first met with suspicion or distrust. For people of average height to become members, they must have a Little Person attest to their character; a Little Person has to go to the Executive Board and petition that the average height person should be allowed membership in the group. In general, LPA is insular to the point of being separatist. If you are not a Little Person, you do not belong. In many subtle ways, they send the message that if you are of average height, in this organization, at least, you are the one considered to be a freak, or at the very least, an outsider. This attitude can be seen from the organization's inception:

It is a logical conclusion that the bigger we are, the stronger we are and the more good we can accomplish for the good of our organization. But at the same time we must be careful and particular who we invite to join our club...Every new candidate proposed should be submitted at a membership meeting and voted on by the members for admission... Automatically it keeps out *undesirable persons, those of ill repute and subversive characters*. (LPA Newsletter, Volume 1, Number 3, 1962; emphasis added)

In another issue of the newsletter, the following was described under the heading

“Unfortunate Incident”:

Every once in a while a person not eligible for membership will, through oversight, gain membership in our organization. This happened during the past year, and as many members know, this individual misused his membership roster. He has been informed that his actions were unacceptable and has been asked to return his membership card and roster and has been removed from the mailing list. *It is hoped that his actions will be viewed more with pity than anger, and not taken seriously by anyone* (LPA Newsletter, Volume 7, Number 4, 1968: 3; emphasis added).

And in yet another issue of the newsletter, with the heading “MEMBERS ASKED TO EXERCISE CAUTION” (emphasis in original):

As a gentle reminder to each of us it should be noted that occasionally a friend of an LPA member's friend [*sic*] get [*sic*] a ‘bright idea’ as to how they can ‘help serve’ the little people. Many times these friends do a priceless service for us but occasionally there are those who are serving only to satisfy their own personal gain or sense of humor. Each of us are [*sic*] cautioned to freely but carefully

release LPA member's name and addresses to non-LPA persons. A basic rule of thumb is "if a non-member especially an average sized person asks for specific persons to contact about LPA, ALWAYS refer the questioner to either your district director or a national officer" (LPA Newsletter , Volume 13, Number 6, 1975: 5; emphasis in original).

And this suspicion towards outsiders is still something clearly seen in the organization today, not just from my own experience, as described at the beginning of this chapter, but in the views that the leadership holds toward outsiders. In my interview with him, LPA President Gary Arnold suggested:

And, you know, I think there's, yeah, I think there is physically kind of a little hesitation around that. Um, just based upon wondering what the person's motivation might be. You know, there's a lot of experiences out there of people being kind of taken advantage of and exploited. And people, others outside of the LP world having an interest in us for not really genuine reasons. You know? So the way that we deal with that is, if there's somebody who is not of our stature, who's not related to a little person, and they happen to become a member, they need to have a sponsor. And they need to have an endorsement from either a chapter president, or from a district director.

Similarly, when I asked Executive Director Joanna Campbell about the organization's attitude toward outsiders, she said:

Yeah, we really, um, I would say that it's not that we never do it, and we do have a few, a few people that fit that criteria. Um, you know, maybe they had a friend who was a little person when they were growing up. Or, you know, we do have a few situations like that, but in general, um, in general, you would have to be a little person yourself or a direct relative of a little person in order to be a member. And that's really just done in order to protect the membership because, you know, the bottom line is that there are some creepy people out there, so it's more that we, you know, it's not that we don't want help, but we have to, you know, first and foremost, we have to protect our members against anybody who like, you know, may exploit them.

She went on to clarify:

Then, but we do offer...medical membership.¹⁵ So if you're a doctor, you know, you're welcome to be a member. So something along those lines. You know, they might be able to come to like local chapter events and then get themselves known, *and if the district director says "yes, they're a fine, upstanding person, they have*

¹⁵ The significance of doctors within the organization will be discussed later in this chapter.

a good heart, they just want to help,” then they would extend a membership to them. (emphasis added)

These examples show how the theme of worry and concern over those of “questionable character,” especially people of average height, gaining access to the group, infiltrating it, and potentially trying to exploit members, was as much of an issue in the early years of the organization as it is today.¹⁶ It is interesting to consider, however, that LPA’s membership is split nearly fifty-fifty between little people and people of average height.^{17,18} Even today, any person who is not a little person and has no obvious connection to a little person, in order to gain access to the group, has to be approved by the board.

It is unclear, though, through the course of my research, whether there was ever really some type of egregious event that took place to cause such a staunch view of outsiders. It seems that the organization’s response is a more general reaction to the fact that there are people who have dwarf fetishes or willingly exploit people of short stature (see later discussion of Dwarf Tossing). It seems that rather than this being a reactive stance, it is rather a prophylactic measure to protect members against not-so-well meaning outsiders, presumably before they are able to gain access to the group and do harm.

¹⁶ It is interesting to note that medical professionals are admitted as members of the organization seemingly unquestioned.

¹⁷ “Average individuals include Parents, Siblings, Relatives, and any one who wishes to support the organization including business establishments, hospitals and non-profit groups” (J. Kay, personal communication, August 3, 2011).

¹⁸ According to Gary Arnold: “Um, you know, it’s hard, there’s never been any real good, uh, uh, quantitative study of exactly how many people there are of people with dwarfism in the country. But estimates are around 30,000 to 40,000 only. And so that limits the number of people in the organization, and yes, so really if you think we’ve got 3,000 of those 30,000, our membership encompasses 10% of the population of people with dwarfism in the country” (LPA Interview with Gary Arnold).

LPA does not seek to create a world where little people are absorbed into the average height community, but instead, to create a world of their own, where they are seen as different and unique in their own right. This reliance on being defined against people of average height merely reinforces already existing hierarchies of power, while simultaneously celebrating an identity separate from the dominant group. In other words, in order for Little People to celebrate their unique identity as people of short stature, the only way for them to do this is to acknowledge their differences from those of average height.

This separatism, the distinction between the AH and LP world, and the lack of involvement of average height people in the organization, puts into sharp relief an “us against them” mentality. One of the critiques of identity politics has been that “it casts as authentic to the self or group an identity that in fact is defined by its opposition to an Other. Reclaiming such an identity as one’s own merely reinforces its dependence on this dominant Other, and further internalizes and reinforces an oppressive hierarchy” (Stanford Encyclopedia of Philosophy 2012). It should be noted, however, that given the visibility of the difference that defines Little People as such, it makes logical sense that the organization would advocate for having a separate culture. The very visibility of their difference makes it futile to attempt to “pass” and separates them from the average height world.

The Case of the Average Height President

In the history of LPA, only one president has been average height. He took office when the elected president and vice president both resigned from their positions. The average height president was in office for one week, when the Executive Committee

elected a Little Person as president to the post (J. Kay, personal communication, August 3, 2011). This mirrors the “Deaf President Now” (DPN) protest that occurred at Gallaudet University in the late 1980s, in which students rallied for the election of a deaf president of the school (Shapiro 1994). While LPA had always had a Little Person as president previous to the average height president taking office, the discomfort and controversy surrounding the week-long appointment shows that LPA strived then, and strives now, to create a unique LP culture and short-statured pride. Like many of the Gallaudet protesters, Little People may have felt that having an average height person leading their group would be a threat to their unique culture and way of life.

Dances, Marriage, and Mating

The nightly dances that take place during the convention are one of the main draws for teenaged and young adult participants. They are also one place in which a separate LP culture is clearly seen. Little People put on their trendiest clothes, their dancing shoes, and bump and grind into the wee hours of the morning (no pun intended). I attempted to gain admittance to the dances on several occasions, but was rebuffed. It was clear that this was a venue strictly for Little People.

These dances are mainstays of the annual conference, given that, even in the early days, the newsletter would proudly proclaim which Little People had met at that year’s convention and were engaged or married. The dances are another way in which LP culture is celebrated and in which the LP legacy is preserved, by providing an opportunity for those of the opposite sex to meet each other; something they might find difficult to do in the average height world.

In the early days of the organization, LPA-facilitated marriages were celebrated in the newsletter, and it is clear that dating and mating was, and still is, one of the prime, albeit unstated, goals of the organization: “[A]nd even though we are not intentionally running a lonely hearts-club, several have found their way to the altar” (LPA Newsletter, Volume 3, Number 10, 1964: 1). One person I interviewed described LPA as a “dating service” for Little People, and said that at the end of her first national conference, she left with a stack of business cards from “eligible bachelors” (Teena; diagnosis unknown; LPA Interview #15).

While occasionally a Little Person will marry a person of average height – known by some in LPA circles as “mixed marriages” (Kennedy 2003: 272; Van Etten 1988) – this is a relatively rare phenomenon, and I was unable to locate anyone at the conference who fit this category; at least it is rare that people will freely admit to it.¹⁹ Some have gone as far as to suggest that “mixed marriages” between Little People and average height people are less successful than those in which both spouses are Little People or both spouses are of average height (Adelson 2005a). While this happens in the organization today, it seems that it was less common in the earlier days of LPA, based on the following taken from one of the newsletters: “If a small person is married to a tall person – it is a family problem! Not the small stature of the little person, whatever his family position or age, but the public reaction to that stature” (LPA Newsletter, Volume 5, Number 2, 1966: 2)!

It also seems that one of LPA’s many goals is to foster the dating and mating of Little People. This can be seen in the following from the newsletter:

¹⁹ Although Adelson (2005a) provided a statistic that of those that responded to an LPA survey, there were nearly equal amounts of Little People married to Little People as Little People married to Average height spouses. Kennedy (2003) confirms this, as well.

Being members of the LPA, this couple has formed an inseparable bond between them which will never be broken, and which accounts for their ability to love not only each other, but also almost everyone else as well. *Being little, one finds bumps and bruises that our taller friends never encounter – and if there is someone to share these bumps with, life is a whole lot happier* (LPA Newsletter, Volume 9, Number 1, 1970: 2; emphasis added).

The above statement clearly shows the organization's view in favor of Little People marrying other Little People, if for no other reason than the common experiences they have as people of extreme short stature (Roloff 1999; Trombino 2008). It is also clear, based on the wedding announcements that fill the pages of the LPA newsletter, that LP-LP marriages are celebrated far more often than LP-AH marriages. This is also seen from the pictures included in the newsletter, and the reticence on the part of those who are married to people of average height to admit to that.²⁰ By creating a culture that seems to stigmatize, or at least look down upon mixed marriages, LPA seeks to further the LP population by making sure that LPs marry and mate with other LPs. In doing so, they also succeed in keeping people of average height out of the organization.

AH Parents of LP Children

One major exception to this exclusion of outsiders is the average height parents of LP children. Most respondents came from families in which their parents were average height. This is not surprising given that “over 80% of people with dwarfism are born to average-height parents with no history [of dwarfism] in the family” (Campbell and Dorren 2006: 3).²¹ This is similar to the Deaf, as nearly 90 percent of deaf children are born into families in which both parents are hearing (Morere 2011). Average height

²⁰ As I found out, but not directly, the current President of LPA is married to an average height woman.

²¹ “If a person with achondroplasia mates with a person with achondroplasia they have a 25% chance of having an average-height child, a 50% chance of having a child with achondroplasia, and a 25% chance of having a child who is double dominant...If a person with achondroplasia mates with an average-height person, they have a 50% chance of having a child with achondroplasia and a 50% chance of having an average-height child” (Campbell and Dorren 2006: 4).

parents of LP children most often found out about LPA from someone in a health care setting, whether it was directly from a nurse, doctor, or social worker, or via an information packet given to average height parents' when leaving the hospital (Kennedy 2003).

Sandy is an average height woman, whose four year old daughter has Achondroplasia. Her husband and son are also of average height, and there is no history of dwarfism in their family. She and her family found out about LPA from an information packet they were given in the hospital, after her daughter was diagnosed as an Achon. Sandy's daughter is one of the most adorable little girls I have ever met. She is full of spunk and attitude.

Like many other average height parents with LP children, the main draw of the conference for Sandy and her family is the free medical consultations. She spoke at length about the importance of this annual event for her daughter:

A lot of the doctors you see here this week only and they tend to have more experience than amongst our local level, where we are, the doctors know that she's the only, she's the only dwarf they see. So, and then, um, the specialists she sees on an annual basis, they might see a few, but not, not enough that really give me comfort. And if something's going on, then I can, um, get in touch with the medical side of the organization, and run it by the LPA... We weren't sure, you know, which doctor she had to see... And we just didn't want to start down a road or where we weren't confident that they knew best how to treat our child. So it was confirmation because then you're seeing a doctor that sees 200 kids annually. So, uh, that was, that was probably the biggest reason to pursue involvement in LPA in the beginning. (Sandy; AH parent; LPA Interview #3)

Similarly, Kristen is also an average height woman with a four year-old-daughter who has Achondroplasia. Her husband is also average height. Kristen's daughter has already

had several major surgeries, and like Sandy, Kristen puts a premium on the medical consultations that are free at the conference.²²

Further, Sandy spoke of the support that LPA provides to the average height parents of LP children:

Um, the next thing has been to get support as a parent, because me and my husband are not little, you know, we don't have family that are little. This is new to us. Um, so to have other parents that are going through what we are. And also to have little people who can provide a different point of view than we have. And, um, beyond that, I'd say, um, um, so that [daughter's name] will have a view of not only our view, but another view from someone who went through it, in terms of that, and can give her an outlook that she can do it. (Sandy; AH parent; LPA Interview #3)

In Ablon's (1988) study of families with dwarf children, extreme views held by the average height parents of the dwarf children were presented. Some parents suggested that had they known they were going to have a dwarf child, they would have aborted the pregnancy, or carried the pregnancy to term, and given the child up for adoption. While it is difficult to know the opinions of non-LPA members, the average height parent members of LPA that I talked to expressed love for and pride in their children, and none expressed regrets about having a child with dwarfism.

Moreover, many of the adult LPs that I spoke with credited their average height parents' love and acceptance of them as Little People with their ability to cope with their difference. Lana said, "I was fortunate that my parents were very supportive. They didn't hold me back in any way. Which was important. They let me be independent, not relying on them" (Lana; Pseudoachondroplasia; LPA Interview #6).

It appears that average height parents of LP children²³ embody what Goffman (1963) referred to as a "courtesy stigma" (31). Unlike the average height population who

²² In fact, Kristen had to cut our interview short because she and her family had a medical consultation to attend.

may have some interest in Little People but are cast aside for having questionable motives, average height parents of LP children are welcomed into the organization with open arms: “Many parents of short-statured children have commented that they feel a family-like welcome and acceptance into the community of LPA” (Campbell and Dorren 2006). Ginny Foos, a well-known member of LPA recently said in a radio interview, “Well, I think, um, at first, it really benefits the parents. I often use the analogy of being on an airplane when the flight attendant says, you know, ‘In case of an emergency, parents put the oxygen on yourself before treating your children.’ And I certainly look at LPA the same” (Pushing Limits 2013; transcribed by author). This suggests that while the organization hopes to get LP children involved in the organization, the first step is bringing in parent members of average height.

Parents play an instrumental role in obtaining membership for their LP children early in life, and despite their height differences compared to LPs, average height parents of LPs seem to feel at home in the organization. This may be because their children are happy and content to be with others like themselves, so too the parents are happy. Some have suggested that the outlook of the child will depend almost exclusively on the outlook of the parent to their child’s short stature (Phifer 1979). This suggests that average height parents bringing LP children to LPA conferences – an environment of being in the company of like others – is a key step in the development of a positive dwarf identity, in which short stature is something to be proud of, rather than ashamed.

Gone are the days when average height parents hid their LP children away, wished they had aborted them, or given their children away. While average height parents may grieve the loss of their expectations for a “perfect child” when an LP child is born,

²³ This also includes average height parents who adopt an LP child.

most parents in LPA today realize that their children are much more than their stature, and with the help and support of LPA, they can live full and happy lives (Roloff 1999; Short Stature Foundation & Information Center, Inc. 1994).

Average height parents have a distinct presence in LPA (as seen by the fact that the current executive director of the organization is an average height parent of an LP child), and are strong advocates for their children, both health-wise and psychosocially. In fact, LP children are vital members of average height families. Many people I spoke with, both average height parents and Little People, themselves, said that LP children were treated the same as the average height siblings and other children in their families (Van Etten 1988).

Pre-implantation Genetic Diagnosis (PGD)

Given that LPA's members view being a Little Person not as a mere medical condition, but rather as a collective identity or culture worthy of being preserved, it is not surprising that they should be concerned with technologies that, in their view, threaten to annihilate it. Therefore, there is a concern, at the levels of both the organization and its members, about the consequences of pre-implantation genetic diagnosis. Pre-implantation genetic diagnosis (PGD) is a relatively new reproductive technology, used in conjunction with in vitro fertilization (IVF), which screens out and destroys embryos with chromosomal abnormalities. Sometimes characterized as the modern form of eugenics, PGD can involve pre-screening out embryos for characteristics such as short stature, and members are concerned that it poses a threat to the continuation of the LP population (Adelson 2005a). The gene for Achondroplasia was discovered in 1994, and since then, genes for many other forms of dwarfism have been identified (Little People of America,

“Frequently Asked Questions: Has the gene for achondroplasia been discovered?”). LPA and its members fear that PGD can be used to destroy embryos found to carry genes or chromosomes causing dwarfism.

One respondent described her concerns:

[I]’ve heard that there are ways to tell if you are gonna have a dwarf, you know, before you’ve even conceived. So I worry about, you know, us dying out, because of, um, people want a normal child. You know, if they find out their baby’s a dwarf, aborting it. I think that’s an issue that comes up. I think, you know, a lot of LPs given up in other countries, and I think that’s happening more and more. (Mary, Diastrophic Dwarf; LPA Interview #4)

And the organization had this to say in a position statement on PGD:

Along with other persons affected by genetic disorders, we are not only concerned as to how our health needs will be met under dramatically changing health care systems, but how the use of genetic technologies will affect our quality of life, medically, as well as socially. What will be the impact of the identification of the genes causing dwarfism, not only on our personal lives and our needs, but on how society views us as individuals? (Little People of America, “Frequently Asked Questions: What is LPA’s position on the implications of these discoveries in genetics?”)

In a small number of cases, pre-screening can be useful in that it can identify whether the fetus of two Achondroplastic dwarfs will be double-dominant – meaning that the fetus gets lethal genes from both parents that will guarantee certain and untimely death – thus saving parents the heartache of having to watch a baby suffer, and ultimately, die

(Adelson 2005a).²⁴ The newsletter has addressed this issue specifically:

But now PGD affords people with dwarfism the ability to reduce the chance of a lethal condition from 25% to 2.5% -- a dramatic improvement. PGD, while not perfect, goes a long way toward releasing dwarf couples from the torture of waiting an agonizing 15 to 18 weeks or longer to learn if their child is viable... When faced with the prospect of passing on a lethal condition to their child, it is reasonable to expect that parents with dwarfism would happily accept – and deserve – any child who has a reasonable expectation of health, regardless of whether or not that child has dwarfism. (LPA Newsletter, Volume 43, Number 2, 2007: 26)

²⁴ Double dominance occurs in 25 percent of cases where both parents are Achons (Adelson 2005a).

Here lies the slippery slope. Even for Little People, PGD does promise some potential benefits. But where does the line get drawn? Is it right for parents to screen for a condition related to dwarfism that will almost certainly cause very early death? Is it right for average height parents to screen out LP embryos? Is it right for LP parents to screen out average height embryos?

While it seems, as stated earlier, that average height parents of LP children have become more accepting of having and keeping such children, there are those who may go to great lengths in the quest for a “perfect child”. Kennedy (2003) cites one study that found that one in four “ordinary couples” would choose to abort a fetus that was known to have Achondroplasia (238-239). It is possible that those average height parents who have an LP child are accepting, whereas when given the choice, average height parents trying to conceive would opt to screen out LP embryos. This pre-screening could also be used in the opposite way, in an effort to preserve LP culture further, for Little People to screen out average height embryos in favor of short-statured ones. A similar debate is had in the Deaf community, in which some people with deafness desire to have a child that is deaf, and use PGD in order to screen out hearing embryos (Sandel 2007).

Given the overall, albeit unstated, goal of the organization to bring Little People together, and to celebrate their unique culture, it is not surprising that any type of medical procedure or social action that would threaten such culture would be avoided. Further, making such technologies available may add more stigma to being a person of short stature, given the availability of procedures that allow embryos to be screened out (Adelson 2005a). In other words, if such technologies become widely available, not using them will create a greater stigma for those who are born or remain short-statured.

The organization is concerned, even on a more general level, about the risks that medical technology poses for Little People. According to Executive Director Joanna Campbell:

I think that the big issues on the horizon for LPA are going to be medical types of things. But um, I think medical, I think where medical science is going is going to be huge in the next five to 10 years because, um, you know, the bottom line is there are pharmaceutical companies working on, you know, a cure for Achondroplasia. And those are going to be issues, they've always been sort of, you know, sci-fi type issues that we never really put much thought into them. And that's going to be something that's going to be huge. Um, in the next five to 10 years. You know, if they do start developing pills and treatments and that kind of stuff. And it's hard because it's sort of, you know, you don't want anybody to have any further medical complications, but yet, at the same time, you're sort of tearing away at what makes, you know, what makes a person with Achondroplasia who they are. You know? So it's a double-edged sword.

It is a constant struggle, for the organization as a whole, and for Little People, themselves, to balance furthering their own, unique culture while living in a world in which being average height is seen as the norm.

The Dilemmas of Identity Politics

Essentialism

In trying to relate to average height society, Little People, albeit unintentionally, create divisions amongst themselves that can be significant. Consider the dilemma of who is considered a dwarf and therefore eligible to be a member of LPA, and who is not. Originally, LPA accepted anyone that considered him or herself to be a dwarf. However, as members sought treatment for medical conditions that accompanied some forms of dwarfism, its master concepts gradually came to be influenced by medicine. Today, LPA accepts one conventional medical definition of dwarfism (less than 4'11") and is divided into sections based on medical diagnoses. Thus, although LPA believes dwarfism is a

culture and *social* identity, rather than a mere medical diagnosis, the organizational boundaries and divisions have become medicalized.

This medicalization creates problems for some members. Of all of the Little People I interviewed, Teena was the most ambivalent about the 2011 conference and her future in the organization. One has to wonder if her lack of diagnosis, which is the main axis of camaraderie and fellowship within the organization,²⁵ was unavailable to her because she does not fit neatly into a “dwarfism type”. It is worth noting that in an organization that focuses on dwarf culture and celebrating the lives and accomplishments of Little People, that even LPA’s self-definition and organization is based on medical definitions of dwarfism.²⁶

To the untrained eye, a Little Person is a Little Person. But the various types of dwarfism do have visible characteristics that differentiate each dwarfing condition, and unwittingly group people together based on diagnosis. The difference, however, is that the focus on the medical side is medical problems that are a threat to life, rather than the functional limitations of living in a society created for those of average height.

Despite the shared culture that LPA boasts, even within the LPA community, differences between Little People can be significant. One of my respondents, Greg, who has Hypochondroplasia (a form of short-limbed dwarfism similar to Achondroplasia, although those with Hypochondroplasia are taller and tend to have fewer medical complications than do those with Achondroplasia (Adelson 2005a)), described feeling out of place at the conference because he is on the taller end of the LPA spectrum (LPA

²⁵ As opposed to aligning by height.

²⁶ According to Executive Director Joanna Campbell, “It’s largely, from an LPA perspective, it’s done based on location. And then, probably, you know, within the group, obviously it’s natural for people to connect that have the same diagnosis, and they’ll probably stay in touch, but we don’t connect them in that way.”

Interview #13). This was a common feeling among those Little People who were considerably taller than most. It was something that even I felt acutely, being 4'11", myself. In contrast to their older counterparts, who organized around the dwarf identity as it is, these younger participants show that unlike their older counterparts, the formation of a dwarf identity can be fraught with complex feelings about oneself in relation to other Little People and to the average height society.

One of the critiques of identity politics is that it essentializes and makes fixed social categories (Bernstein 2005), and "may come to have a disciplinary function within the group, not just describing but also dictating the self-understanding that its members should have" (Stanford Encyclopedia of Philosophy 2012). This is seen in Teena, who does not have a definitive diagnosis for her type of dwarfism, and Greg, who is at the taller end of the LPA continuum, despite having a diagnosis of Hypochondroplasia. For the purposes of the group, the convention has been for people to organize themselves based on their type of dwarfism. Even though LPA, at the organizational level, has defined a Little Person as someone who is 4'10" or under, with a medical condition responsible for their short stature, divisions across diagnostic lines have become common. Such splintering into narrow categories as a result of identity politics has been noted in the literature (Bernstein 2005).

In other words, "Just as dominant groups in the culture at large insist that the marginalized integrate by assimilating to dominant norms, so within some practices of identity politics dominant sub-groups may, in theory and practice, impose their vision of the group's identity onto all its members" (Stanford Encyclopedia of Philosophy 2012). In this way, identity politics and this division into diagnostic categories, obscures the

diversity and plurality of the experiences of Little People, regardless of diagnosis. This creates problems when someone who does not neatly fit in a dwarfism box attempts to gain membership to the organization, or an existing member feels out of place because they are taller than the LPA norm.

Identity politics, along with essentializing, often privileges or takes as most salient one identity over others (Gamson 1995). This may cause Little People to view their height as the key component of their life, and if this is called into question, say through the use of medical technology to eliminate or alleviate signs of dwarfism, can cause a person to question their identity altogether. Privileging one identity guarantees that people will have strong feelings about it, but also may mean that they only think of themselves in terms of a singular notion of identity (Brubaker and Cooper 2000).

Employment Issues

Despite the positive responses to reality television show portrayals of Little People mentioned earlier in this chapter, the legacy of people with dwarfism being used and exploited in film remains. The organization was started, after all, by a dwarf actor, and most of the original members were employed in the entertainment industry. This dependence on the entertainment industry for steady jobs for Little People continues today. One person I spoke with went as far as to suggest that every person with dwarfism has been involved in the acting profession at some point in their lives. Thus, despite the fact that Little People attempt to create a positive identity and avoid being caricatured, their economic dependence on the entertainment industry forces them to work with – or even accept roles within – the very industry that caricatures them.

The situation seems to be evolving slowly in this regard. The roles for dwarf actors have become more serious, such as the work of Peter Dinklage, who had a prominent role in “The Station Agent,” and won a Golden Globe in 2012 for his role in the television show “Game of Thrones.” However, he played a dwarf in both parts. Even in the more serious roles, Little People are still being typecast as dwarf characters. And then there are actors like Verne Troyer, of “Austin Powers” fame, and Henry Nassif, of “Howard Stern” fame, who have acted in much less serious and questionable roles.²⁷

Unfortunately, while Little People may try to escape the entertainment world, jobs in the field are lucrative and plentiful. According to a 2003 analysis of the LPA membership database, a sampling of 3,276 members over the age of 21 cited acting and entertainment (N=100) as the fourth most populous occupation for Little People (J. Kay, personal communication, September 1, 2011), suggesting that despite trying to distance themselves from the entertainment world, many Little People are still fully entrenched in that type of work. However, such jobs may ultimately lead to Little People being cast in a negative light, and may reinforce the very stereotypes that those who are members of LPA seek to eliminate.^{28,29}

²⁷ Regardless of roles, in the past it may have been that dwarf actors were sought out, not so much for their acting abilities, but for the spectacle that could be caused by their short stature (Adelson 2005b).

²⁸ The most oft cited occupations were Retired (N=318), Homemaker (N=171), Teacher (N=111), Secretary (N=72), and Accountant (N=67). It is interesting to note that the most populous occupations were those in which people were not employed outside the home; those listing themselves as disabled was relatively small (N=34). Having so many people listed as “retired” suggests that while the organization is targeting the younger generation, older members in the organization still predominate. The only caution about this data is that respondents were not given a list of choices and were asked to self-identify their occupation (J. Kay, personal communication, September 1, 2011).

²⁹ It is interesting to note that while many from the older generation work(ed) for state agencies and are often employed in large corporations to deal with accessibility and disability related matters, many from the younger generation are employed as teachers, social workers, and other helping professions (this is a common trend among people who get involved in social movements, according to Snow and Soule (2010)). These subtle and not-so-subtle differences between the older and younger generations show how the organization has had to re-visit old issues and grapple with new ones.

Exploitation: The “M” Word and Dwarf Tossing

The term “midget” was once used to describe those of proportionally short stature (Moneymaker 1989; Weinberg 1968). Today, however, it is considered a pejorative term that takes people back to the era when dwarfs were side-show freaks and guinea pigs in medical experiments under the Nazi regime (Adelson 2005a; Adelson 2005b; Kennedy 2003; Koren and Negev 2005). Originally, LPA was known as Midgets of America, but the name was quickly changed to reflect a more politically correct modicum of operation. It is interesting that an organization that at the present time so discourages the use of the term willingly used it in the original name of the organization. LPA President Gary Arnold, when I interviewed him, gave a thorough explanation of this:

[O]riginally actually it was called “Midgets of America.” Um, you know, back in the day, you know, several generations ago, the word “midget” was more benign than it is now. Uh, for some time, I think it was used, kind of as an umbrella term, the way “little people” is now. The umbrella term describing all people of short stature, um, it has kind of gone out of favor over the past few generations. Mostly because I think because of the very close association between the word “midget” and kind of a stereotypical, objectifying meaning, representations of little people. And so, as a result of that association, the word has just taken on an ambiguous meaning. Um, but I think, even long before there was awareness, awareness around the word “midget”, that they changed the name...And I think there’s some difference of opinion on why the name was originally changed. Um, the story that I heard was that the word midget was too exclusive. It referred to just one type of dwarfism. So they wanted, uh, to be more inclusive of people with all types of dwarfism. And, uh, and so they used the term “little people”. Other people, though, will say that it was changed early on because of the negative connotations. So I don’t know which story is closer to what actually happened.

This change in nomenclature from midget to dwarf and now to the more politically correct term of little person or little people, is symbolic of identity politics, providing greater inclusion for those who are a member of the group (similar to the move from gay and lesbian to queer identity), all the while keeping strict boundaries, as discussed earlier, against those who are not (Stanford Encyclopedia of Philosophy 2012).

Currently, the LPA has a campaign in which they want use of the “M” word eliminated from modern day vocabulary. This is almost like the initiative several years ago which sought to ban the “N” word, although representatives of LPA say that they do not want to ban the “M” word, as much as they want to increase public awareness that the “M” word is derogatory, and viewed by Little People as a slur, from a time when LPs were even less accepted in society than they are today. In 2009, the organization also lodged a complaint with the Federal Communications Commission (FCC) for the use of the word midget, occurring 12 times in a single episode of the “Celebrity Apprentice”, asking the FCC to add midget to the list of words that cannot be used on television.

Along with this, there are seven high schools, all in the Midwest, that boast “the midget” as their mascot. The Dickinson (North Dakota) Midgets are a surly looking bunch. LPA has tried to meet with the school boards of all of the districts, trying to convince them that the midget image is a derogatory one. But those from one of the towns say that they love their mascot and do not want it to be changed. An LPA member quoted a school board member at one of the schools declaring: ‘I will die a midget’. Using Little People as a “mascot” is not an uncommon occurrence, but it is nonetheless extremely degrading (Van Etten 1988), and this can also be seen in the explanation of dwarf tossing below.

Dwarf tossing is an activity that typically takes place in bars, in which average height people pick up a Little Person and throw them as if they are a shot put or a javelin. Dwarf tossing was first mentioned in the newsletter in 1986 under the headline “DWARF-TOSSING CONTEST HALTED IN CHICAGO” (LPA Newsletter, Volume 23, Number 1; see also Van Etten 1988). By getting their voices heard in the press, the

LPA had a direct hand in stopping the Chicago contest from occurring (Van Etten 1988 speaks at length about dwarf tossing). It was banned in Florida in 1989, but legislation introduced to repeal the ban in 2011 renewed efforts of the LPA to oppose the repeal, and speak out against the barbaric nature of dwarf tossing. Ultimately, the LPA was successful in helping to revoke the repeal of the ban, and the bill died in committee in 2012.³⁰

A statement put out by the LPA said: “While dwarf tossing is an extreme risk to the individual, it also objectifies the entire dwarf community” (Little People of America 2011a). Further, “Historically, members of the dwarf community, who were not involved in dwarf tossing, were put at risk because of the message of objectification sent by dwarf tossing. Members of the dwarf community reported being fearful while alone in public due to the new risk of being picked up or threatened to be used as a piece of equipment” (Little People of America 2011a). One author asks why dwarf tossing: “Why were dwarfs chosen for tossing, rather than women or children of the same weight? The dwarf seemed to have been placed in a category distinct from humanity – somewhat human, but not quite” (Adelson 2005a: 283). Dwarf tossing, therefore, is another remnant of the long history of dwarfs being exploited (Adelson 2005b). As the use of the “M” word and dwarf tossing indicate, discrimination against Little People is alive and well in our country.

Some might argue that LPA is tackling an issue that may seem superficial or minor, as opposed to putting resources into battling employment discrimination³¹ or other

³⁰ In Peter Dinklage’s 2012 Golden Globe speech, he dedicated the award to Martin Henderson, a Little Person in England who was paralyzed after being dwarf tossed ([HuffpostTV 2012](#)).

³¹ Kennedy (2003), who is an AH man whose daughter is an Achon, tells the stories of Michael Ain and Paul Steven Miller, both Achons, which show that employment discrimination based on short stature is

issues. This choice is both strategic, and is consistent with the stated goals of the organization. The organization does not take part in political lobbying, does not have members on staff who are representatives to politicians, and this move is consistent with the organization's desire to reach out and raise awareness about dwarfism to the general public. Tackling employment discrimination would require legislative and potentially legal action, and lobbying, working within the system, whereas going after "the 'M' word" is more of a cultural pursuit – and perhaps a goal that may seem more easily attainable. Further, employment discrimination, while it may be widespread, seems to be more of an individual issue, unlike the use of the midget mascot and dwarf tossing, which are more clearly derogatory actions against the group of people with dwarfism as a whole.

The Ideology of Choice: Use of Enhancement Technologies

People with dwarfism experience many health problems. Among the more common medical problems are sleep apnea, bowleggedness, frequent ear infections in childhood requiring tubes, hydrocephalus, delayed motor skills, increased risk of Sudden Infant Death Syndrome (SIDS), spinal stenosis, and obesity³² (Adelson 2005a; Committee On Genetics 1995; Haga 2004; Shirley and Ain 2009). Most Little People with Achondroplasia are known to be of "normal" intelligence and have "normal" life expectancies (Committee On Genetics 1995; Haga 2004). Achons can also have complications with childbearing and anesthesia.

alive and well. Ain, an orthopedic surgeon, applied to 30 medical schools and 14 residency programs, and was rejected by all of them. Eventually, he did find a medical school and residency program that would support him. In the case of Miller, who graduated at the top of his class from Harvard, he applied to 45 law firms and did not receive a single job offer. He eventually found work, and became heavily involved in the disability rights movement. But their successes were hard won. See also Van Etten (1988) for more examples of employment discrimination based on short stature.

³² Some doctors suggest that LPs double their height in inches and that is the maximum weight they should be. For example, an LP who is 30 inches tall should weigh no more than 60 pounds (Adelson 2005a).

Thus, because members had significant medical problems, the organization felt obliged to meet those needs by providing information about medical treatments, which became an important part of LPA. This dependence on medicine may seem to contradict LPA's firm position that short stature is not in itself a disorder that needs to be treated. Executive Director Joanna Campbell expressed this particularly well when she said:

Um, so, we're not, um, into seeking a cure, we're not into fundraising to seek for [*sic*] a cure or provide research into curing, you know, quote unquote, any type of dwarfism. It's, you know, the main mission of LPA is that you just live the best life that you can, and you arm yourself with all the knowledge that you need about, you know, any programs that might help you, or any adaptive products that might help you, and you know, you have a great life. That's the main mission of LPA.

As discussed earlier in the chapter, there is a distinct (and important) medical side to the organization, in which doctors are available for consultation. But the organization is clear that these doctors focus on treating the health problems that can come with dwarfing conditions rather than treating height. This makes sense when we look at the views and opinions of both the membership and leadership in response to the use of human growth hormone treatment and extended limb lengthening surgery.

Human Growth Hormone (hGH)

We have gained the respect of many, and without medication, we are growing in stature (LPA Newsletter, Volume 3, Number 11, 1964: 2).

Virtually all the Little People I interviewed emphasized that for most LPs, hGH is not used; it tends not to be very useful in increasing the height of Achondroplastic dwarfs, although studies are being done to see if it might be useful (Key and Gross 1996; Shirley and Ain 2009), and some studies even suggest combination therapy using both

hGH and limb lengthening surgery (Haga 2004).³³ hGH is effective in cases of endocrine disorders, but is not as effective in treating bone disorders. hGH does, therefore, have efficacy in increasing the height of Pituitary dwarfs (Pituitary dwarfism is an endocrine disorder caused by an isolated growth hormone deficiency (Adelson 2005a)). One respondent said:

I have several friends whose parents have given them growth hormone, and it disproportions their body. So instead of growing proportionately, for instance, it would, their spine would grow, their back. And then the spine is overly long, and then that causes a lot of problems. And then it causes, it can also cause, um, facial hair in the boys, so you get, there can be a lot of different things. So it has a very, it's politically, and I think it's more an issue of the parents not accepting their children. Because if you're, I'm 3'11". So if I'm 3'11" and I have some type of hormone, and I'm going to get three inches, I'm still a little person. (Lana; Pseudoachondroplasia; LPA Interview #6)

One of the keys to the above statement, and something that I heard from many of the Little People I interviewed, is that even if hGH worked in the case of Achons, they would still most likely be considered short. Even if Lana would have taken hGH and gained a foot of height, which is rare for treatment with hGH generally, growing from 3'11" to 4'11", she would still be little, although at the very tall end of the LPA spectrum. Others felt that, while personal choice abounds, LP pride should overrule feelings to change oneself to fit society's definition of "normal":

I don't feel that it's something that, I mean, it's something that, I think it's a personal choice for everybody. My take is we were born this way for a reason. I think that, obviously when you start, being able to walk and stuff, and those are things that are a necessity, I feel like the growth hormone type of thing to make you grow would be more to satisfy what society thinks you should be. Um, you know, society wants us to be tall. So we're gonna accommodate what society wants. I'm not in support of that. I think it's important that we, um, be prideful in ourselves, and not in a bad way. Um, so yeah, I don't like limb lengthening and I'm not in support of growth hormone therapy, unless it was to treat, um, like a medical

³³ For children with idiopathic short stature, hGH is recommended for those who are three standard deviations below mean height. Untreated Achons tend to be six to seven standard deviations below the mean for height (Shirley and Ain 2009).

condition that was like a [*sic*] life or death, or it would improve your quality of life. Which maybe, you know, somebody may feel being taller would improve their life. I think, I'm fine with my height. I'm 3'8". (Mary, Diastrophic Dwarf; LPA Interview #4)

Unlike Little People, themselves, for average height parents of LP children, the prospect of hGH treatment has a particular draw:

In the first part of the packet of information I got, it had LPA in it. And it also had information about that. So there was a moment where I read through that and was like, 'Wow! We are going to fix this!' And, um, and then as I read more into it, um, I came to the understanding that that's not my decision. That needs to be her decision. And it needs to be done at a time that is appropriate. After she's grown as much as she can. After she's had time to deal with that. In her teens. And, and then with a lot more information than we have at this time. So it went from okay 'Let's do this, let's do this,' to, you know, let's find out all we can to learn about this. And it isn't for now, it's for later. And it's for her. And we'll support her in the decision to do that, making sure that all the information is on the table, and we'll stick by her no matter what. And make sure she is making the decision for the right reasons. (Sandy; AH parent; LPA Interview #3)

Despite initial excitement, Sandy, like many others I spoke with, emphasized personal choice above all else. Many worried about, in particular, the fact that hGH therapy needs to be started at an early age before children could make a choice about whether to be treated? "Well, my feeling is that it's a personal choice. Um, the only real problem I see with it is that, for it to be effective, it needs to be started at an early age..." (Jon; Precocious Puberty; LPA Interview #2). This rhetoric of personal choice that was so pervasive in LPA is in stark contrast to the other organizations under study here (see next two chapters).

Still others were more pointed in their views:

Completely against it. Completely against it. When I was in Shriner's in 1969, um, my parents brought me in because, again, I was very, very bow-legged. And one of their first questions, um, the doctors suggested to my parents growth hormone. And my mom said, 'We brought our child in to have corrective leg surgery. She's our child. She is no different than our other four children, who are of average height. We do not want any growth hormone.' And I firmly believe, I

am completely against any growth hormone. It just, I don't know. I think, um, a lot of research needs to be done, and I don't believe that a little person should be a guinea pig because they can. We don't know what is going to happen. Um, the torso could grow, and the limbs could stay. Or the limbs could grow and the torso could stay. And therefore then more medical complications are going to develop from that. And really, again, to gain three or four inches, it's simply not worth it. In my eyes, and in my mind. It's simply not worth it. I am completely happy with my body frame of 3'6". Completely happy. (Monica; Cartilage-Hair Hypoplasia; LPA Interview #7)

Growth hormone was rarely mentioned in the LPA newsletter, and then, only in passing. The only more than passing mention of it was in 1985 to report on the debacle with the pituitary-derived version, which caused "Mad Cow" disease. Although the organization does not specifically address hGH as it does limb lengthening (see below) – and a range of opinions can be seen regarding hGH – it was most common that people emphasized personal choice, waiting until the child is able to decide for themselves. This is congruent with the organization's stance. It is embedded into LPA culture that there is a distinction between medical necessity and medical significance, and procedures that are seen as neither. hGH is one such technology. If there was some medical use for it to help those with dwarfism, other than increasing height, it would seem that it would gain more support in the organization than it has.

But changing one's height to fit society's definition goes directly against the LPA goal of preserving LP culture. LPA President Gary Arnold summarized the issue: "So we don't, just like we don't make an effort to go out of our way to speak out against limb lengthening, we're not going to speak out against growth hormone."³⁴

³⁴ This can also be seen in the medical workshops that take place throughout the conference. In a workshop about the genetics of dwarfism, for example, the presenters all referred to themselves as being of "normal" height. There was a distinctly clinical bent to the panel, suggesting that dwarfism is a genetic "mistake". The panel did emphasize, however, a significant departure from the view of some genetic counselors, a move away from personal responsibility that having a child with dwarfism, even if one or both parents are dwarfs, is like playing "Russian roulette". In fact, members of this panel worried that the increase in pre-natal testing will cause average height parents to abort fetuses that are known to have dwarfing conditions.

Extended Limb Lengthening (ELL)

The response of interviewees to limb lengthening surgery was much the same as it was for hGH. Most respondents emphasized personal choice, and this was seen as aligning directly with the organizational stance. While limb lengthening surgery is used – one of my respondents pointed out the gait of someone across the room and told me that, that person had been “lengthened” – the organization’s stance remains rather equivocal.³⁵ The Extended Limb Lengthening Position Statement put out by the Medical Advisory Board of LPA states, “The following position summary is *not intended to either advocate for or condemn extended limb lengthening*. It is meant to be a measured summary of information that may be of value to members of the small stature community and members of Little People of America” (Little People of America 2006; emphasis added). The statement goes on to describe the indications of extended limb lengthening, which include treating leg length discrepancy and short stature.

As is the case with hGH, respondents emphasized personal choice, in the case of an LP child, letting them decide for themselves.³⁶ One respondent said, “It’s a personal choice, one that I can’t quite understand but will respect. I don’t like when parents claim that their eight year old or their 10 year old made the decision – aside from that, I’m sure the parents wouldn’t let their child’s opinion carry that much weight” (Brenda;

One member of the panel emphasized, however, that dwarfism does not necessitate medical treatment, as a condition such as cancer does. Despite the usage of clinical language at times, the overall conclusion of the panel is that people with dwarfism “don’t need to be fixed”, and that there should be a clear emphasis on function and mobility, rather than increasing height.

³⁵ Despite the fact that those who have had limb lengthening surgery are obvious to some, I was unable to speak with anyone who had, had it done. There are several reasons for this: 1) the person was under the age of 18, and I only had Institutional Review Board (IRB) approval to talk to adults, and 2) people that have had it done are unwilling to talk about it, or do not want to bring further attention to themselves.

³⁶ Some have suggested that it is especially dangerous to approach teenaged LPs with this option because the teenage years are an especially tenuous time for any person in that age bracket, and that as adults, they will come to view their dwarfism more positively, and will therefore have no need for the surgery (Kennedy 2003).

Achondroplasia; LPA Interview #14). Other concerns included still being considered a little person, even after surgery, and others worried that such an aggressive procedure would cause functional limitations down the road, which have been documented in the literature on Achons and limb lengthening surgery (Price 1989). One respondent said, “Again, completely against it. There is no need to be, if you’re going to be, even if it’s a foot, you’re still considered a little person. And it’s not worth, down the road, those individuals, are going to have medical issues. Arthritis, the ability to move is going to be limited...” (Monica; Cartilage-Hair Hypoplasia; LPA Interview #7). Another respondent said, “Overall, why put all the focus and energy on the individual? You’ve got to adapt. And in many cases that’s impossible” (Jon; Precocious Puberty; LPA Interview #2). One LP who considered having the surgery said:

Limb lengthening, that’s a tough one. I debated having that surgery... Luckily, my mom gave me the option. She took me, she told me, you know, I could have it. When I was younger. And they showed a video of it and everything. They break the bone and push it up. And having to learn how to walk, and having to go through the physical therapy, and all that, I just, I don’t know. I thought that it was pretty bizarre (Greg, Hypochondroplasia; LPA Interview #13).

Greg ultimately did not have the surgery, and one can only imagine what would have happened if his mother would not have given him the choice, and would have had the surgery done anyway?

Another respondent suggested that it is actually the job of LPA to create an atmosphere that makes Little People realize that they do not need surgical enhancement to make them taller:

But sometimes people need that extra bit of, uh, surgical, um, manipulation to make them feel more comfortable. So it all depends on the situation. Like I was saying, personally I don’t think I could do it to myself. Personally I don’t like pain [laughs], so, but if a person, um, I hope that person, or individual, has looked at all the avenues of research, and come to the LPA conferences, and seen other

little people as they are, and have accepted themselves. I hope that, that would teach them that you don't need to become somebody else. You're fine the way you are. And I'm hoping, too, that it's not just parental influence making this child go through that type of surgery. I think it should be a personal, personal and individual, uh, decision, not, uh, influenced by the parents. (Adam; Cartilage-Hair Hypoplasia; LPA Interview #1)

While this interviewee encapsulates many of the statements of other respondents about personal choice and letting children decide for themselves, it is also important to note the emphasis he places on LPA's role in swaying such decisions.

Both of the average height parents I interviewed illuminated the difficult and complex choice of limb lengthening. Kristen and Sandy both emphasized personal choice:

You know, if I think about that when she was born, and did it, maybe I would've, because my daughter's had five surgeries in four years. But, um, none of them have really impacted her life so far, um, and there's [*sic*] a lot of complications regarding Achondroplasia that are not being short. I mean, that's the least of the problems, in my opinion. I mean, she has sleep apnea, both central and obstructive, she has to wear a CPAP [continuous positive airway pressure] mask for both of that [*sic*]. . . she had her tonsils and adenoids taken out because she has obstructive sleep apnea, um, she has whole sets of tubes from surgery. So, um, you know, it doesn't do anything to help with the major, in my opinion, the major medical problems. It just makes you taller. And my concerns are not only all the complications regarding that, *but also then you're just sort of a tall dwarf. And what do you do with that? You don't really fit in anywhere.* And I don't know. I don't know how it would help or hurt. You know? I, so, and it, and it, you know, it takes at least two operations, if not more than that. It's a number of operations to put a kid through. I certainly wouldn't do it without her permission, and not until before. (Kristen; AH parent; LPA Interview #12; emphasis added)

Here Kristen emphasizes the many serious health problems that her daughter has as a result of Achondroplasia. She also describes the fact that if one becomes a "tall dwarf," they may actually have more rather than fewer problems fitting into society, because they may not be average height, but they may also no longer be considered an LP, either. In fact, being a "tall dwarf" may cause a Little Person to no longer fit into the LPA context,

given how obvious looking one of my interviewees suggested those who had limb lengthening surgery are. Further, all of the signs of dwarfism will still be there, the characteristics that are common in Achons will still be present, other than profoundly short stature. Kristen also talks about personal choice, and suggests that she would want her daughter to make the choice for herself, rather than Kristen making it for her. In relation to this, she said:

And the problem is, Dr. [name], if you look at his webpage, he wants to do it younger. He wants to do it younger because you get better results. And I get that. But it's a tough thing to decide, to make the decision about your kid getting in there when, you know, it's something they don't need. So you have this big operation for your kid, and they're going to be in a lot of pain. But at the same time, like, you know, something that's generally pretty much cosmetic, I kind of feel like their environment can be adapted. (Kristen; AH parent; LPA Interview #12)

She went on to say:

So, I'm still looking into it because she's probably going to need an operation for her legs anyway to straighten them...*but um, you know, it seems like a long, I guess it's, a long run for a short climb, and all you get out of it is to be taller...* So, you know, it's not going to make your body any better. Your legs being taller. Your arms are still gonna be short. So, I, I'm, I'm generally, I'm not interested in it. But certainly as she gets older, if that's what she really wanted, and I felt she had the emotional and mental capacity to make a decision like that, which is challenging, because most kids that are 18 don't. I think you have to be exceptionally mature to make a decision like that, and so, I would need her, I would have to really make sure she understood all of the long term, as well as short term, side of that before I suggested it. (Kristen; AH parent; LPA Interview #12; emphasis added)

Here Kristen suggests that she would be more likely to consider limb lengthening surgery if her daughter was having some other type of surgery on her legs. In other words, it would be more acceptable to tack on limb lengthening to a procedure that is deemed medically necessary to improve function than to do it on its own. While this slightly blurs the lines between treatment and enhancement, it is in keeping with the organization's view of procedures that are a medical necessity versus those that only increase height.

In LPA circles, some have compared limb lengthening for dwarfism to cochlear implants available to deaf patients (Adelson 2005a). Making taller dwarfs not only is a threat to LP culture, but it also potentially adds more stigma, not less, to those who undergo it, because aside from longer limbs, the other signs of dwarfism are not diminished or changed, and neither are the non-height related health problems that come with it. As recently as 2005, the physical, social, and psychological impacts of limb lengthening surgery have not been identified. This lack of follow-up information makes the decision to have limb lengthening surgery especially tenuous, considering that some Little People feel that those who have had the surgery tend to walk differently, in a way that sets them apart from other LPs.

LPA President Gary Arnold suggested that ELL has not been the “galvanizing force” for those of short stature that cochlear implants have been for the Deaf community. Arnold felt that there is not as much pressure surrounding the procedure. If anything, I would argue, there is more pressure not to be lengthened within the LPA community than there is to have it done, despite LPA’s overall stance of advocating for personal choice. This is seen in how those who have been lengthened are readily identifiable by the way they look, and the overall secrecy of those who have had it done.^{37,38}

³⁷ A workshop focusing on orthopedic issues stressed the general, equivocal stance of the LPA in regards to limb lengthening surgery. It was suggested that any surgery for purely cosmetic reasons is the choice of the family and child, and decision-making will be based on the age of the child. Overall, the doctors on this panel emphasized a concern with function rather than a height increase. The two doctors that spoke on the panel suggested that if a child is happy – especially an Achon – he or she should be left alone; as long as the child is “short and happy”, there is no indication that surgery is an absolute. The panel also emphasized that “People in LPA don’t want to be medicalized”, which may be true, but is ironic given the popularity of the medical consultations at the annual conference. While I was unable to attend multiple medical workshops held during the same time, one may extrapolate from the two workshops discussed. What both workshops had in common was that they were consistent with the general views of LPA, that being short is

To summarize: Because its members often need medical treatment, medicine has entered into LPA. At the same time, LPA's leaders and members believe that short stature is not a disorder that needs treatment, but rather a difference that is the basis for a distinct culture and identity. LPA resolves this apparent contradiction by emphasizing that they advocate treatment of health problems rather than short stature, itself. Technologies designed to make LPs taller, particularly limb lengthening, pose a particular problem to Little People because they fly in the face of the view of short stature as a difference to be celebrated rather than a stigma to be eradicated. While many of its members expressed emphatic disapproval of these technologies, the official position of the organization stops short of taking a firm stand against them, as is done in the Deaf community. Perhaps because of a need to maintain alliances with physicians, the organization avoids an avowedly anti-medical official stance, and thus adopts the compromised position of "personal choice."

Short Stature and Disability Rights

When Billy Barty began the organization in 1957, he did so with the express goal of creating a group identity for those of severe short stature (Kennedy 2003). The goal of the organization, however, has changed, as it has come to adopt a more disability rights-centered focus. For LPA, one particularly thorny dilemma is the question of whether, and to what extent, the organization should align itself with the disability rights movement. On the one hand, the leadership of LPA acknowledges that, to be effective advocates,

a viable option, that height alone is not an indication for extreme medical treatment, and that personal choice should take precedence when making decisions about medical procedures and treatment options.

³⁸ For a first-hand account of limb lengthening, see DiDonato (2012). Notably, DiDonato, although 4'10" after limb lengthening, is not a member of LPA. Also, while the organizational stance of LPA is equivocal on limb lengthening, DiDonato describes in her memoir some of the "hate mail" she received from other LPs, telling her that her decision to be lengthened was a disgrace to the LP community.

they need to form alliances with other movements that fight stigma and discrimination. The disability rights movement has been a well-established and powerful force in America and England, and has been instrumental in winning victories against discrimination, beginning with the passage of Section 504 of the Civil Rights Act in the 1970's, and culminating with the Americans with Disabilities Act (ADA). Adopting the perspective of disability rights has the potential to provide powerful allies and to give the LPA a well-developed parlance and ideology to discuss stigmatization, architectural and employment discrimination, selective abortion, and other issues that Little People face. On the other hand, it also is called into question by those who are Little People, but who do not view dwarfism as having a disability, and do not view themselves as disabled.

The LPA Newsletter shows that since the Americans with Disabilities Act was passed in 1990, there has been significant discussion about it within the organization. For LPA, the more long-term direction is to become more involved in the disability rights movement. The move to a more disability rights and civil rights orientation is not surprising given that LPA has acted in similar ways and dealt with issues similar to other groups, such as the Deaf and African Americans. Further, the use of identity politics is commensurate with the disability rights movement in that the notion of identity politics was first used to describe the activism by people with disabilities to convert their stigmatized identity into a source of pride rather than shame (Anspach 1979; see also Bernstein 2005).

One respondent, however, spoke at great length about how this orientation has not been accepted by all members:

Well, the goals have shifted. Um, when um, in the '50s when it was founded, it was probably one of, and still is, one of the few, um, advocacy groups for

disability, that was formed by disabled persons. Without parent involvement, without medical involvement, and all that stuff... *Um the organization is still grappling with the whole issue – are we disabled? Do we want the label of disability? And that’s really what it boils down to. Because on the one hand, there are services, there are rights...beneficial to all of us who are short statured. On the other hand, it leads to the kind of, it can lead to a kind of dependency and passivity that is really antithetical to the whole mission of the organization, which is, you know, we’re capable, we have talent, we have skills, knowledges [sic], and we should compete, provided it’s a level playing field.* (Jon; Precocious Puberty; LPA Interview #2; emphasis added)

While many members have functional limitations that cause them to view themselves as disabled, not all types of dwarfism come with conditions that cause one to be disabled.

There are some members of the organization who do not view their short stature as a disability, and hesitate to accept that label. From my experience with the organization, this matter is one of the issues in which there was the least consensus, and an issue that the organization will continue to confront, especially given the current president of the organization’s involvement in the Disability Rights Movement. Despite this, however, there are members who clearly view LPA through the broader lens of disability rights: “Anything so that the individual adapts to the norms of the community. And of course, we’ve adopted the opposite policy here. You know, we’re not going to do that. It’s more necessary that the environment will be adapted to fit us. Just like all the other disability groups. So, we follow that tradition” (Jon; Precocious Puberty; LPA Interview #2).

This increased interest in aligning with other disability rights groups can be seen as a strategic move on the part of the LPA to broaden their message and appeal.

However, due to the lack of agreement on the issue, LPA’s stance about disability rights and involvement has again been dominated by the theme of personal choice: “Um, disability, you know, to describe yourself as disabled, is, is um, you know, I guess it’s a

personal choice, and so not everybody, especially historically, has wanted or identifies with that term” (LPA Interview with Joanna Campbell).

LPA President Gary Arnold described how he thinks the organization is changing, overall, in this regard:

I think it’s changing. I think traditionally, yeah, people didn’t identify as people with disabilities, they identified as people with dwarfism. And, you know, there was stigma around disabilities, just as there’s a stigma around dwarfism. Um, you know, people thought a disability is an added thing that’s wrong with you. And people thought: ‘Well, I don’t have any mobility issues, I don’t have any other type of issues, I’m just short. That doesn’t mean I’m disabled.’ And, um, I think that’s slowly changing. Um, you know, so the change probably started with, um, the passage of what are civil rights laws, protecting people with disabilities. And so, people, you know, broadly thinking of civil rights issues, not as a special-needs issue. Um, so, and just kind of choosing the mindset around disability. And, uh, and so I think it’s just slowly changing, and people are identifying as people with disabilities, as well as people with dwarfism.

It is clear that the views of the leadership on this issue are described more explicitly than the membership, overall. Both President Gary Arnold and Executive Director Joanna Campbell seem to be endorsing the move forward toward a disability rights agenda. But again, the membership is not so equally balanced on this issue. Do those LPs who do not view themselves as disabled sacrifice their individual identity, in favor of group dynamics? Or can the organization sustain its disability rights focus, even though not all members may be in full agreement of its utility and representation?³⁹

Like others who have asserted their identities via identity politics, including other disability rights groups, most LPs would not change their stature, despite discrimination

³⁹ Recently, the LPA was part of a nationwide effort to support the ratification of the treaty of the United Nations Convention on the Rights of People with Disabilities. According to the e-mail sent to members, “If ratified, the treaty will extend protections to people with dwarfism traveling abroad and will give LPA a tool to advocate for the rights of people with dwarfism in other countries” (LPA Today Online, November 2012). While this is another attempt at moving toward a disability rights focus, it should be noted that the protections would cover other countries and would not directly impact those living in the United States.

experienced in various areas of life. As was written in an early issue of the newsletter: “Personally, if I were given the power by some miracle to change and be of normal size, I would not make this change, and I think most of you, on careful consideration, would feel the same” (LPA Newsletter, Volume 3, Number 11, 1964: 2).

Conclusion

As has been suggested, the main goal of LPA is to create a positive culture or collective identity for Little People. The organization does this by holding an annual conference in which Little People from around the country and world are able to come together. Further, activities that take place at the conference, such as the fashion show, talent show, and athletic competitions, not only allow Little People to be involved in activities that they have previously been barred from by the average height population, but also celebrates their unique contributions in these areas. Attention drawn to LP culture on reality television shows, and through the international adoptions of LP babies also suggests a more positive view of LPs, both within and outside the LPA community.

Along with boasting a positive identity, Little People seek to have their own, separate culture, an identity politics which borders on separatism (Anspach 1979; Bernstein 1997). They do this through strict membership requirements and a distinct suspicion of outsiders, and by encouraging members to date and marry other Little People. One notable exception to this is the average height parents of LP children, who find favor in the organization because of their relationship to a Little Person. This is also seen in the organization’s concern over the annihilation of LP culture through the use of enhancement technologies. While the use of human growth hormone and extended limb lengthening are viewed as a personal choice by the organization, there is grave concern

over the use of pre-implantation genetic diagnosis to screen out embryos that are found to carry short stature genes.

Despite the creation of a separate culture, as seen at the conference, LPA still has to interact with the outside world. While LPA does not want to medicalize short stature, there is an acknowledgement that some members have real medical problems that need to be treated, while simultaneously not wanting short stature to be viewed as a disability. Medicalization can also be seen in the unquestioned allowance of doctors as members of the organization, and by offering free health consultations. The organization also inadvertently accepts an arbitrary, socially constructed definition of what it means to be short statured, further accepting the views of the outside world, a common pitfall of groups that utilize identity politics (Bernstein 2005). In other words, it is prudent for them to create alliances with the outside world to accomplish broader goals, yet the balance between the LP and the outside world creates dilemmas for those who do not fit in to LPA, for using medical technology, and forming alliances with disability rights groups without explicitly accepting short stature as a disability. While the leadership and membership are very much in agreement on the view of the use of enhancement technologies, such as human growth hormone and extended limb lengthening, as a personal choice, and pre-implantation genetic diagnosis, as a threat to LPA culture, they do not agree on whether or not short stature is a disability.

These dilemmas are characteristic of identity politics. The sociologist would be remiss not to point out that the designation of dwarfs being 4'10" and under is a social construction. That definition is arbitrary. What about those with dwarfing conditions who are over 4'10" and those without conditions who are shorter than 4'10"? Where do they

fit in? The distinction between the LP world and the average height world is tenuous, at best. What about people like Teena (diagnosis unknown; LPA Interview #15), who feel at odds with LPA because of her lack of diagnosis? And what about people like Edna, who I will discuss in more depth in the National Organization of Short Statured Adults (NOSSA) chapter (chapter 4), who feels at odds with LPA because she is at the taller end of their continuum? And what of people like me, who straddle the line between insider and outsider? Where do these people fit, and how does one make sense of their short stature and its primacy in their lives? Some of these variations will be discussed in later chapters. In the next chapter, I will look at an organization that expresses positive views of enhancement technologies.

While the yearly conference provides an oasis for Little People, with stepstools at the bathroom sinks and counters at Starbucks, after the magical week in Disneyland, these niceties disappear. And it is back to reality. “Fitting in” is an elaborate ruse. The fairy godmother only gets you so far. She has the power to gather people together, but not to change societal attitudes; the problem does not lie in small bodies, but small minds.

Chapter 3:

MAGIC Foundation

Introduction

The first event at the MAGIC Foundation conference is an exhibit, in which all of the pharmaceutical companies that produce human growth hormone are present to showcase their unique products. The atmosphere is carnival-like. It is geared towards children, with a variety of activities, such as an ice cream stand, rock climbing wall, balloon animals, face painting, and a variety of arts and crafts. While the kids are having fun, parents are being inundated with information about growth hormone. There are also t-shirts and backpacks with pharmaceutical company insignia, and the backpacks are filled with Pop Rocks candy, Silly Bands, and temporary tattoos. One of the pharmaceutical companies even had a mascot walking around – a person turned into an EasyPod – adding to the carnival-like atmosphere.

These events suggest that an important part of MAGIC's activities is to make children grow taller and to provide parents with information about drugs that can make this possible – all the while packaging these activities as “fun” for children. But the organizations' leaders adamantly insist that height is not MAGIC's primary goal. The goal of the MAGIC Foundation, they argue, is to promote children's health, and height is merely a proxy or symptom of more serious health problems. However, the organization's name, “MAGIC,” which stands for Major Aspects of Growth in Children,

and the organization's motto, "Children have a short time to grow and a lifetime to live with the results," suggest otherwise. Moreover, for parents, especially those whose children have been diagnosed with Idiopathic Short Stature (ISS) or Growth Hormone Deficiency (GHD), their children's height seems to be their key concern.

It is impossible to attend MAGIC's conference without being struck by the contradiction between what the leaders contend is the organization's primary goal – Health – and the views of parents attending the conference and the many talks and exhibits showcasing drugs that make short children grow taller. As the organization's activities suggest and as I will argue, it is the goal of normalization – making children become "normal" – often at a great cost – that drives the organization forward, and the involvement of the pharmaceutical companies in the organization is one way in which the goal of normalization is achieved.

These contradictions between the official views of the leadership and those of the rank-and-file, between the organization's stated ideology and its actual practices are the subject of this chapter. Drawing on my interviews with MAGIC'S leaders and founders, I first describe the history and goals of the MAGIC Foundation as depicted by its leaders. Next, based on my own observations of the organization's activities and interviews with parents, I describe these activities and the views of the parents who participate in them. While all organizations and social movements are subject to tensions or contradictions between the "official" legitimating ideology and the "unofficial", in the case of MAGIC, these contradictions are particularly glaring. While these contradictions are quite apparent, the more challenging task is to explain why they exist. As I suggest in the conclusion, the many tensions in MAGIC reflect a deep ambivalence in a culture that

uses enhancement technologies in a relentless pursuit of the normal but is deeply ambivalent about the quest for “normalcy” and the technologies it uses in service of that quest.

MAGIC Seen through the Eyes of Its Leaders: Creation Stories

The MAGIC Foundation is a non-profit organization that was started in 1989 in Illinois. It was started by three women, all of whom had children diagnosed with Growth Hormone Deficiency, as an outgrowth of the Human Growth Foundation (HGF).⁴⁰ Their stories often assume a typical form. As mothers, they “knew” something was wrong that kept their children from growing, yet struggled for years to find a diagnosis. Their quests for information were frustrated by doctors uninformed about the causes of short stature and misdiagnoses. As one of the Founders of the MAGIC Foundation notes:

My daughter was diagnosed with Growth Hormone Deficiency in 1985. And it took me three years just to get her diagnosed. And when she was diagnosed, there was...another support organization out there called the Human Growth Foundation...So when my daughter was diagnosed, I thought that people needed to know that if children weren't growing correctly, um, that they were, that it could indicate that they have something major going on with them. When I was fighting to get her tested, they thought she had thyroid problems. So when they told me that she not only had thyroid problems, she had Growth Hormone Deficiency, I was shocked. I had never heard of growth hormone. (*MAGIC Interview #2*)

Determined to learn more about Growth Hormone Deficiency, she turned to the only existing organization, the Human Growth Foundation, only to find that “these were not parents of affected children. They were just Board people who were either business people who were trying to help the Foundation, or they were affected by the different disorders.”

After discovering that the Human Growth Foundation was not primarily a parent

⁴⁰ It was the intention of the author that the Human Growth Foundation also be included in this research. However, multiple attempts made to contact the organization were not successful.

organization, and after meeting two other mothers who were also unsatisfied with what HGF had to offer, the three mothers decided to go off on their own and create an organization that focused on growth disorders, and catered specifically to the parents of affected children. What started as a support group to help three mothers of children with Growth Hormone Deficiency cope, grew into something much larger.

When another of her children was diagnosed with McCune-Albright Syndrome, this Founder turned to another mother who suggested that the new organization adopt a broader mission. She said, ‘Why don’t we just found MAGIC to be for children with any kind of growth disorder? Because I don’t think I can do this by myself.’... [name] was versed in dealing with parents and chapters, and my background was marketing and, and I guess publishing. So the two of us were a big complement to each other, to get MAGIC started. That’s basically how it started” (*MAGIC Interview#2*)

The organization was literally started in the home of one of the Founders: “[I]t started in her son’s room [laughs]. In fact, moved to her den, expanded past that to her basement, and then we had to get a building [laughs]. She got tired of taking over more rooms in her house [laughs]” (*MAGIC Interview #2*).

The personalities of the founders of MAGIC are dynamic. It is immediately apparent that they are passionate about what they do; they did, after all, start the organization because of the experiences they had, had with their own children, to make sure that other families did not have to go through the same things they did. These founders blazed a trail; a trail that some people find difficult to follow, even today. In their online stories, the founders stress how difficult it was for them to give their children injections, especially given that the needles at the time were large, and the injections

quite painful. But in the quest for growth, they soldiered on, and other concerned parents began to flood the organization for information.

The current leadership of the organization is made up of the Founders Board, which includes the three original founding members, the Board of Directors, four full-time staff members – an Office Administrator, the Executive Director, the Chief Executive Officer (a position currently held by one of the Founders), and the Technical Education Director (a position currently held by one of the Founders) – and Division Consultants, who are volunteer moms, who are the “go to” people for each of ten diagnosis groups. The organization is organized by diagnosis and does not have a regional component to it. The Boards meet twice a year in person, while conducting a variety of business online throughout the year.

From an organization founded by three members, the organization grew dramatically, and now includes members in every state. While there are 25,000 people in MAGIC’s database, it is not clear how many of those are active members; however, the annual conference typically attracts 800 to 1,000 people. Although MAGIC does not collect the demographic characteristics of its members, my observations at the conference suggest that there is even less diversity in MAGIC than there was in LPA. A possible explanation for this lack of diversity is that Caucasian families may have better and greater access to healthcare, have the money to incur the expense, not only of treatment, but also of traveling to the conference (on a yearly basis), may be more likely to be carriers of the illnesses that the Foundation focuses on,⁴¹ and may have a greater need to

⁴¹ When asked, the Foundation refused to give me information on the prevalence of each illness within the organization, in an effort to “protect” their members.

connect with like others on the basis of characteristics other than race. Families attending the conference come from all over the country.

Unlike LPA, which is a “cradle to grave” organization, the MAGIC Foundation supports young children and their families (Adelson 2005a). Therefore, the majority of the people that I interviewed were the parent or parents of young children. The majority of members of the organization are mothers, particularly housewives, although I talked to one couple and one father while I was at the conference. This make up of members makes sense given the history of the organization, since it was started by mothers of young children. Additionally, there are some members who are the parents of now adult children, and also adults who suffer from some of the disorders that the organization focuses on.

The fact that the organization was started by and is sustained by mothers is also a big part of organizational ideology, both from the Founders and the parents that are currently involved with the organization. As one of the Founders said:

We were basically just moms and housewives, and um, we had no clue what we were doing. We were just thrust into it because, if you get told that your child has something that you’ve never heard of, and it’s experimental drugs, and they don’t know what it’s going to do to your kid, but without it, shortness aside, they could have a heart attack, they could lose bone strength, they could go blind, they could go all this stuff. You panic...And so we kind of comforted each other because the three of us, independent of each other and without talking to or knowing each other, all made the same decision...So, we kind of kept house and understood that everything was going to be okay through that friendship, essentially. And that’s what we had to do because there wasn’t something called the Internet. (*MAGIC Interview #2*)

And as one member said, “I say never underestimate the power of a mom” (Rod; *MAGIC Interview #11*). Although MAGIC actively solicits professional and corporate sponsors,

its leaders emphasize that the core of the organization is not medical professionals or corporations, but parents who were, or are, trying to do right by their children.

Goals and Mission: The Leaders' Perspective

Sharing Information and Education

As their narratives reveal, the leaders embarked on a long and lonely quest for information. Once their children's conditions had been diagnosed, they suddenly faced a bewildering diagnosis. They knew nothing about possible treatments or where to find this information. Given their difficulties finding information about their children's conditions, it is not surprising that MAGIC, the organization they founded, would make educating parents its major goal. As one of the Founders explained:

We don't want to tell parents what they should or should not do with their children...because we're not medical professionals. We want to empower them to make whatever decision is best for them and their child. Some families, they don't want to treat the disorder. That's fine. That's their issue. They have to live with the consequences. You know? Um, but we feel like the more education we have, they're more empowered to make good decisions, what's going to be best for their child long-term...So it's more of a long-term educational [*sic*]. We want to offset the damage that medical conditions can cause by delayed diagnosis. So if you can check the child when he's got a brain tumor the size of a golf ball, as opposed to a softball, you've made a huge difference in his life. (*MAGIC Interview #2*)

Much of its website is devoted to education. The visitor can click on the name of one of several diseases to obtain detailed medical information about the major conditions associated with short stature. The website also provides information to parents about how to measure their children's height accurately, and how to read and interpret growth curves. The website also includes information about the organization and sections for professionals. But it is clear that it is written with an eye toward providing parents with information about short stature.

In addition, MAGIC sends a weekly e-mail to members, which synthesizes new and current research studies, divided by condition, which provides information for parents that they may not be able to get on their own.⁴² The e-mail also serves as a way to communicate with members about announcements and other organizational happenings. These e-mails came to serve as an interesting piece of data, providing insight into organizational ideology. Along with the weekly e-mail, there are three newsletters that the organization publishes quarterly; one for affected adults, one for parents and grandparents, and one for children.⁴³

Perhaps the most important source of information is the Foundation's centerpiece: The Children's Educational Conference, which has been held yearly since 1995. At the conference, parents can attend lectures and sessions on a wide variety of conditions: Congenital Adrenal Hyperplasia (a lack of enzyme production from the adrenal gland, which causes short stature), Growth Hormone Deficiency (the pituitary gland does not make enough growth hormone, causing short stature), Insulin-Like Growth Factor Deficiency (hormone deficiency causing short stature), McCune-Albright Syndrome/Fibrous Dysplasia (a rare condition characterized by bone disease and endocrine issues), Optic Nerve Hypoplasia/Septo Optic Dysplasia (underdevelopment of the optic nerve, also includes pituitary deficiency), Panhypopituitarism/Tumor (decreased secretion of hormones produced in the pituitary gland), Precocious Puberty (early puberty, which causes final adult height to be shorter than normal), Russell-Silver Syndrome (characterized by poor growth and one side of the body being larger than the

⁴² Along with the conditions covered at the conference, the weekly e-mail also provides information about Cushing Syndrome, Thyroid conditions, and Turner Syndrome. At the conference, children with Idiopathic Short Stature are lumped in with children with Growth Hormone Deficiency.

⁴³ Unfortunately, the organization does not have an archive of these publications, so I was only able to access and analyze those that were published while I was taking part in the organization.

other), and Small-for-Gestational Age (small size caused by differential/lack of growth in utero).

The educational sessions that are the main purpose of the conference are divided by condition, and most are lead by doctors. There are also events tailored to children, such as field trips and a crazy hat party. Two general sessions were held on the last day of the conference, one about how to keep MAGIC going, and the other about building awareness of growth disorders within the media and the general public. There are also several networking sessions built-in for each disorder type, allowing those present to meet other families who are dealing with the same diagnosis, to exchange information or provide emotional support. MAGIC also holds a separate weekend conference designed specifically for adults with Growth Hormone Deficiency, which was started in the last ten years.

Whether the sharing of information and education is happening in-person, online, or over the phone, MAGIC seeks to support parents, provide them with information, and empower them to do what is right for their children. The leadership describes organizational support in this way:

We're parents-founded, our Board is made of parents, so our philosophy and our guiding principles are completely parent-focused. That means we want to do what's best for the parents and the children and the family unit. We're not out there to make a name for ourselves... We're simply out there to service the families. And the reason is because we've been in those shoes. We've all cried many nights, we've all been scared to death of having to put a needle into our own child's body, you know, especially when it's a tiny, little body... It's horrifying. You don't expect that when you get pregnant. You hope it's not going to happen. But nobody in your family's said to you, 'Have you ever heard of this disease?' And then all of a sudden, you're faced with them [*sic*]. So, our entire guiding principle, our mission... everything, is completely centered on what is best for that family... So it's really important for us to make it as easy on, not just the child, but on the family as a whole... Because every single child that we can help, it's personal. *It's not just that one child that we're helping, the family gets better, and generations of that*

*family get better.*⁴⁴ (MAGIC Interview #2; emphasis added)

The opportunity for parents to support each other, which will be discussed in greater detail later in this chapter, is another one of the main goals of the organization.

Insurance Strategies

One of the key barriers for MAGIC parents is obtaining insurance coverage to pay for the very costly treatments prescribed to their children, such as human growth hormone. In fact, about one-third of the calls that the organization receives are from parents regarding insurance problems. Growth hormone is notoriously expensive; the estimated final cost is \$20,000 per inch of height gained. This is especially true for children who are on it for a significant period of time, and those who go on to need maintenance doses as adults. One mother estimated the cost of her daughter's treatment to be \$5,000 per month. Insurance is one of the key arenas in which the medical necessity of growth hormone comes into question. Most families were frustrated that often, decisions regarding insurance approval of growth hormone treatment were made by doctors in specialties other than endocrinology, and in some cases, decisions were not even made by medical professionals at all, but rather by insurance companies, who, in their view, had little understanding of the importance of growth hormone treatment.

There was a session at the conference devoted to insurance issues and the myriad ways parents could work the system in their favor. In the insurance workshop, parents are coached on how to deal with insurance companies. Parents are told that they should "Suit up for battle," to expect their first claim will be denied, and that Medicaid is "coverage of last resort."

⁴⁴ This almost sounds like eugenics; as if short stature is the worst possible characteristic and getting rid of it will make the world a better place.

The workshop also coached parents on how to file an appeal of an insurance denial, as many of the parents have faced. It was suggested that they share the child's story and include; photos of comparison to other kids of the same age and younger that are taller, a letter written by the child, and growth charts and medical justification. According to the presenter, these "heart-wrenching" stories give MAGIC a 90% success rate on claim denial appeals. It was also suggested that parents try and stockpile growth hormone so that if there is a lapse in insurance coverage, they will have a back-up supply, in order to avoid a lapse in treatment, which could cause a child to lose precious inches.

Despite their best efforts, some parents were ultimately unable to get insurance companies to pay for growth hormone treatments. These parents, too, developed strategies, such as substituting a less costly bioequivalent hormone, but nevertheless were forced to finance their children's treatment themselves.

Height Versus Health

One of the main stories that permeates the organization, a creation story of sorts, is a narrative that justifies a form of outreach the organization started early in its history: Conducting height screenings across the country, in both medical centers and schools. Two of the Founders would literally get in the car and travel across the country. As described to me:

But if you're getting, if you're, in the early days, [name] and I used to do screenings, where we'd go into school systems and we would offer free growth evaluations, with growth charts, in effect measuring [the] height... And we were doing a growth screening in Little Rock. And this dad travelled for four hours, one way, just to come see a couple of moms who were giving a free growth screening. Because for five years, he'd been trying to find out why his son wasn't growing right. Well, we were just fortunate enough to have the screening at the local children's hospital. And one of the pediatric endocrinologists was volunteering his time for us. And we weren't doing anything in-depth. We were just measuring kids, plotting them on the growth chart if they were normal. 'And here, take your growth

chart, check everything on there, they're doing great'... If they weren't, they'd say, 'You know, follow 'em up with your local pediatrician, and maybe, if they're not increasing their growth velocity, which is how much they grow each year, maybe you want to see if your pediatrician will give you a referral to a specialist.' Never directly naming anybody or anything. Just, you know, double check on it. And this dad came, and he, his son was so severe, that the pediatric endocrinologist that was volunteering said, 'I need to see your son in my office Monday morning.' Now this was Saturday morning. And so, the dad stayed in town, got a hotel room, didn't have much money, I don't know how in the world he afforded to do that. And Monday morning, his child went through all this testing, and he had a brain tumor the size of a softball in his head. That had been missed by dozens of doctors. Literally. They ended up doing emergency surgery on him, to remove the tumor. He lost an eye in the process. Because the tumor was so embedded into his one eye. And then they had, and it was cancer, so they had to do chemo and radiation after that. (*MAGIC Interview #2*)

According to the leaders, similar instances have occurred several times over the years that the organization has been in existence. The Founders' belief that height is often a symptom of a serious medical condition is presented as a reason that the organization is so important. These stories also illustrate how the leaders frame the goals of the Foundation. On numerous occasions, the leaders insisted that the organization is more focused on health than height.

The leaders also try to distinguish between helping children that "actually need" growth hormone rather than those who do not. As one of the Founders said:

And people seeing that children are supposed to grow at which they do, and they don't understand that if they're not growing two inches or more a year, that it can be an early warning sign of a brain tumor, which can be really serious. You just expect your kids to grow. Like your [referring to me] parents thought, 'Oh, she's cute and little and everything.' But if you aren't growing two inches a year, they say, 'Oh, she's just going to be little,' you know, not really doing anything... And now with the Internet and social media, it makes it much faster. It also makes our work four times as hard, because you do have a lot of people who, because for cosmetic reasons, think oh, 'I can get my kid bigger.' We're not for that at all. Not at all. We don't care about a child's height for cosmetic reasons. At all. We care about a child's height as an indicator of their overall health. You know? It's just that, like if you had a big letter C, a neon C that says, oh, you're getting cancer, you'd pay attention to the C... For a growing child, the height is that glowing C. It's an indicator, a visual indicator. But everyone thinks that if you're worried about

your child's height, that it's just because you want to give them an advantage that they don't think other kids have, or whatever, and that's not the case. (*MAGIC Interview #2*)

The above description is interesting because it is somewhat contradictory. On one hand, MAGIC suggests that parents should take any lack of growth in their child seriously, and pursue medical intervention, while simultaneously suggesting that there are parents out there who merely want their child to be taller, and that is not something that the organization supports. By bringing growth disorders into strong relief, not only is the organization feeding into parental fears that something is wrong with their child, but they also may inadvertently be making it harder for those who actually do have something wrong with them to get help. As one of the Founders explains below, doctors may pass up nearly all pronouncements by parents about concerns over their child's growth because it is such a common concern, which is often unfounded. And yet, MAGIC encourages parents to seek out answers about their child's growth or lack thereof, and is, in effect, contributing to the glut of parental concerns about height that doctors receive.

As one Founder explained:

Children should grow. That's what they're supposed to do. If they don't, then you have this huge world that opens in front of you as to what it could be. And because most parents want their child, for athletic reasons, for physical, for sports or whatever, they want their kids to be the biggest and the best, because there is so much competition in their mind, then you have a lot of people say this mom is just worried about her child. I doubt there's a pediatrician in this country who doesn't hear at least 30 times a day, 'Is he growing okay? Is she growing okay?' Basically you're going to turn a deaf ear to it. You have to. You can only take that concern, you know, so often. But then you get these little kids like you've seen [that I have seen at the conference], and you're going to miss them...So, it's a challenge. It's a big challenge. (*MAGIC Interview #2*)

This points to a major dilemma that the organization faces; getting help to the children who truly need it, without catering to parents who are strictly pursuing growth hormone

treatment in the quest for a perfect child. But as I will show, since the distinction between Growth Hormone Deficiency and Idiopathic Short Stature is tenuous, who is really in need of growth hormone treatment is often difficult to determine.

By emphasizing that short stature can be a symptom of a more serious medical condition, the leadership of the organization is, in reality, medicalizing the problem (Conrad 1992). And the use of the brain tumor example discussed earlier suggests that the leaders of MAGIC almost see short stature as a disease, in and of itself.

Normalization

According to its leaders, a key goal of MAGIC is to make children feel normal. As one of the Founders said, “You know, it’s nice because they have some joy and be normal. They don’t get that anywhere else” (*MAGIC Interview #2*). A mother of one of the ISS children said, “Kids get to come here and feel completely normal. And know other kids that get shots, and have the same types of things, and they kind of grow up together” (Judy; *MAGIC Interview #9*).

The leadership claims that this is the goal of similar groups: “There’s one common thread that runs among every single non-profit and essentially, every single group, out there. And that is, you’re not alone. So if you have purple eyes, and you’re a member of the purple-eyed purple-eater group, all of a sudden you’re the normal one, when you’re in that group” (*MAGIC Interview #2*). It should be noted, however, that while other groups may derive some sense of normalcy from interacting with those who share similar situations, not all groups share MAGIC’s overall goal of trying to become normal by changing one’s body to conform to a “norm”. As is seen in the cases of LPA and NOSSA, their goal is not normalization, but an identity politics that borders on

separatism and changing our culture to be more accepting of short people (assimilation/equal rights).

One has to wonder where the feeling of abnormality comes from in the first place. In my opinion, one of the reasons that these children may feel abnormal is because they have been placed under a medical microscope by their parents. Some studies have provided indirect support that treatment with human growth hormone can in fact lead to increased feelings of stigma and difference, and can have negative psychological effects on children (American Academy of Pediatrics 1997; Churchill 1994; Diekema 1990; Grumbach 1988; Macklin 2001; except those where the research has been sponsored by pharmaceutical companies). In some ways, it makes sense that MAGIC is telling parents not only to make their children abnormal, but then to seek normalization at any cost. While these may seem like contradictory purposes, as sociologist Erving Goffman (1963) suggested, normalization and stigmatization are “cuts from the same standard cloth” (130). In order to normalize, de-normalization must occur first. In other words, in trying to normalize, MAGIC first has to medicalize short stature; and normalization and medicalization are two strategies that may be incompatible with one another.

George as a Symbol of “Normalcy”

These days, a key piece of the MAGIC puzzle is George Chmiel, who has come to play an increasingly prominent role in MAGIC. George is in his thirties and works for Merrill Lynch. It is hard not to believe in George. He looks like a Greek God and has a heart of gold. He started running ultra-marathons in order to raise money for MAGIC.⁴⁵

⁴⁵ An ultra-marathon is any type of distance running longer than a regular marathon, which is 27.2 miles. Ultra-marathons take place all over the world, often in places with extreme weather conditions and extreme terrain.

While he is not a parent, he has been truly changed by the experiences of his business partner, whose daughter was diagnosed with Panhypopituitarism.⁴⁶

Unlike LPA, MAGIC accepts the help and support of people who are not directly related to the organization. In fact, they have elevated George to “guardian angel” status, as one of the Founders of MAGIC espoused throughout the conference. To some extent, however, this valorization is not surprising. In fact, it makes a great deal of sense. Having George be the “poster child” for MAGIC accomplishes a chief goal of parent members: they want their children to “fit in”, to not be teased, and to be viewed as “normal.” Despite George’s lack of height-related problems, being the good looking, toned, successful, athletic type, are all things that these parents wish for their children. Therefore, in the quest for normalization, George has become a key symbol of normalcy.

According to one of the Founders:

Okay. Then I’ll tell you about George. He’s running this summer. George is 30 years old. He’s a Vice President of Merrill-Lynch. He’s single. And he is drop dead gorgeous. Too bad I’m not 20 years younger. But anyway...Um, so, George did this phenomenal thing. He raised 50-some-odd thousand dollars. And then he did another one. And then he got MAGIC moms to walk to Nashville in a half-marathon last April. And now he’s running in Nepal in November with seven friends from Merrill-Lynch. His goal is to raise a million dollars for MAGIC. He doesn’t even, he’s not even married with a kid. He’s just doing this for his Goddaughter...Because of that ethic, he really believes in us big time. And he’s just been just wonderful. (*MAGIC Interview #2*)

While George said that many people doubted his ability to successfully run an ultra-marathon, George’s goal is “[T]o really just get the message out on MAGIC, and talk about some of the injustices that have taken place, not only in the medical

⁴⁶ PanHypoPit, as it is referred to within the walls of MAGIC, is a rare disorder in which all pituitary hormone production is decreased, which can cause short stature and a wide variety of other problems.

community, but [also] the insurance industry” (*MAGIC Interview #10*).⁴⁷ He explained that parents feel like he has done something wonderful for their children. And this is visible. He has attained celebrity status within the organization, walking around with cameras following him and people constantly coming up to meet him. He said of the experience: “So, I mean, having all those families coming to me and befriending me and welcoming me into this whole MAGIC family, I mean, it’s changed my life...I’m so inspired by the Founders, [name] and [name], and all the work that they do, and all these families and kids. It’s a very special organization” (George; *MAGIC Interview #10*).

Originally, he did not see running ultra-marathons as being something he would do more than once, but he explained:

It’s really like I said earlier. Just, you know, seeing, every conversation I’ve had always comes back to the same thing. They were lost until they found MAGIC. They didn’t have the right doctor, they weren’t getting the right treatment, they weren’t getting the right diagnosis... ‘And when we found MAGIC, we got a game plan, we got, you know, connected with this network of folks dealing with the same stuff. We had people that our kids could hang out with’ ... And then getting to meet all these families, seeing that they really do appreciate what you do. I mean, you know, it’s hard when you work a 70-hour-a-week job. I don’t have a lot of free time. And I’ve put a lot in on the side, that no one knows about, training, you know, when I come home at 10 p.m. and I decide to go out for a run, and I’ll run ‘til midnight. And I’ll give up a weekend to go out and do a six-hour run. You know, that’s, I mean, no one knows that. But at the end of the day, they appreciate so much what I’ve done. And that just makes me want to do more... I loved it, I fell in love with the sport. And I fell in love with these people. And so now it’s, you know, something I want, and it’s a big part of my life for the foreseeable future. (George; *MAGIC Interview #10*).

George has also attracted a lot of attention outside of the organization, which has been good press for the organization itself, and for George, as well:

None of us were really big runners or anything. But now we’re doing something so extraordinary, and it’s a great way to see the world. And when you do something so crazy, and you literally put your life on the line, you know, it’s a

⁴⁷ See the discussion earlier in this chapter about insurance issues and the strategies the organization provides to parents in dealing with insurance companies.

good story to tell. And most people will stop and be like, you know what, that's kind of cool. What's the agency? Who's the MAGIC Foundation? Okay, well, you know what, that's awesome. I'd love to hear more. Here's a hundred bucks. (George; *MAGIC Interview #10*)

Ultimately, though, George puts things into perspective, comparing his struggle to become a marathon runner to the struggles of many of the children in MAGIC: "We're going to have to go through problems and we're going to be battling, while voluntarily, for only six days, not for our entire lives. You know, there's [*sic*] some parallels there, and, you know, we want to get that message across, of doing something, you know, above and beyond" (George; *MAGIC Interview #10*).

One might wonder why a tall, good-looking, athletic man would become the public "face" of an organization dedicated to treating conditions associated with short stature in children. To understand George's symbolic function, it is important to understand MAGIC's complicated attitudes toward publicity. As one of the Founders explained, MAGIC "tends to cloak all of our families. They're not going to be publicly visible". Further, she explained how MAGIC has had opportunities to go on national TV, "the cream of the crop," but have refused:

From our vantage point, it's almost like prostituting the child's medical condition. It's telling them something's wrong with them. And we don't, we don't want them to feel like something's wrong. We want them to feel like they're good people, this is just their challenge in life. We don't put people on television in a wheelchair and say, 'Look how pitiful this child is.' You know, help us. Then the child didn't have a wheelchair until they're ready to go on television. (*MAGIC Interview #2*)

She further explained that while the organization has been approached to be more public, they have refused to put children on the "front lines." They do not want the children of MAGIC to be "poster" children for "pity".⁴⁸ This stance can also be seen as key to the

⁴⁸ This makes one think about the Muscular Dystrophy Association (MDA) yearly telethon, which has received backlash in recent years from "poster children" about the exploitive nature of the organization

normalization that the organization strives for. By putting children on display, “sensationalizing” them, and “prostituting” their medical conditions, MAGIC would be sending the opposite message than what it is trying to create within its protective walls. Normalization cannot be achieved if children are thrust into the spotlight as different and in need of pity and special treatment. However, from another perspective, it is possible that this may be the indirect message of treating children with growth hormone in order to make them taller. Moreover, as I have noted, several studies have found that growth hormone can have negative psychological consequences for children (American Academy of Pediatrics 1997; Churchill 1994; Diekema 1990; Grumbach 1988; Macklin 2001). This research suggests that for some children, growth hormone treatments may increase stigmatization.

So how do you raise money for children that the rest of the world may never really see? The children do not have to be seen; that is where George comes in. Instead, George has become a “poster child” of sorts, as far as the organization is concerned. And it seems like some of the appeal that exists for George is in the notoriety that has come from his ultra-marathon running to raise money for MAGIC.

In short, George serves several symbolic functions: As a symbol of the struggles to attain physical perfection, as a visible symbol of the normalcy parents strive to attain for their children; and as the attractive public face of an organization in need of public support. Of course, one might ask who is truly being served? The children? Or the parents, who need to feel like they are not alone in their quest for a perfect child? George

(The Kids Are All Right, “About the Video”). It also brings up questions about who is really being served by the organization.

appears to be both a charismatic leader for MAGIC, as well as a foil for the children that MAGIC wants to help.

Advocacy

MAGIC's leaders are very conscious of the organization's public image. In fact, both the leadership and the rank-and-file of MAGIC feel that a significant roadblock is the growth hormone controversy that has taken place in the athletic arena and the "bad press" it has received in the media. As one of the Founders said of the general public:

I don't think that, um, what they believe is accurate information, and by accurate, I mean medically proven stuff. Um, that the majority of people are of that mind. But people don't understand, they believe the hype, they believe the stories in the newspaper, that so-and-so is a baseball player and he bulked up and everything using growth hormone or steroids. A lot of people still think growth hormone is a steroid. It's not. (*MAGIC Interview #2*)

A negative public image can be quite consequential. In fact, several parents suggested that too much negative publicity can jeopardize their own chance of getting growth hormone for their children:

[A]nd the reason I do it is to build awareness. Because there's so much bad stuff about growth hormone in the media. And the more stuff that comes out like that, the less likely my kid is going to be to get her medicine... And then get denied by insurance, because of the misuse and because of the bad press. So I, um, I try to get the good side. There's no doubt it's medically necessary for my child. (Judy; *MAGIC Interview #9*)

A desire to combat this negative publicity, coupled with a need to recruit members and supporters, is what leads MAGIC to view one of its major goals as "educating the public on what a growth disorder is" (Tracy; *MAGIC Interview #6*). MAGIC's leaders are also keenly aware that some members of the public may not view short stature as a condition that requires medical treatment. For these reasons, MAGIC's leaders are careful to craft a public frame or narrative that emphasizes that health, rather than height, is the

organization's major concern and that short stature is usually a symptom of a "growth disorder" or a real disease that must be treated.

Negative reactions from outsiders who do not view short stature, or what they believe to be the chief problem of the child, as a condition worthy of treatment, can cause significant problems. Outsiders, therefore, cannot be considered "wise others" (Goffman 1963), but rather are "naïve others" (Schneider and Conrad 1983), as they do not have all the facts of the situation, and may have many preconceived and potentially incorrect notions – whether their own or influenced by media accounts – about the predicament of the short child and his or her family. In fact, the situation is just the opposite. Outsiders may contribute to a feeling that parents have to defend the parenting of their child because they are treating their child with growth hormone. Some of this backlash could also come from the fact that parents, rather than doctors, administer injections to children. The leadership of the organization, however, can be seen as "wise others," since their own children have gone through the growth hormone treatment process. Further, the leaders of MAGIC help parents navigate, not only the obstacles created by doctors and pharmaceutical companies, which are particular to growth hormone treatment, but also the outside world, in general.

At times, MAGIC's efforts go beyond managing the organization's public image. While one of the Founders claims that the organization does not engage in lobbying of any sort because of their status as a non-profit organization, actual occurrences suggest otherwise. As was described to me:

Um, we have, um, three years ago, there was some legislation that was going to impact almost every single one of our kids. And it had to do with, um, um, growth hormone, and then some of the professional baseball players got arrested for abusing it. They were trying to make it a schedule three narcotic, which meant

every person who needed to use growth hormone legitimately, was going to have to go back to the doctor every 30 days to get a new prescription written, and manually take the prescription to a pharmacy to get it filled. Well, that's problematic for many reasons. Number one, pediatric endocrinologists are overbooked, overworked, as it is. There's an 80% shortage of them. Which means somebody's gonna have to give. So, families that may have a five hour drive in Montana, to the local endocrinologist, who only flies in once every six weeks, couldn't get the medicine for their kids. Long story short, because of this legislation, we were in communication with all of them, asking them to rally up. (*MAGIC Interview #2*)

The leadership claims that: "No, we don't do any lobbying at all. As a matter of fact, that legislation thing that we were talking about was mostly parent-driven." But clearly this is not the case, since MAGIC contacted other similar organizations in order to try and get more support on their side. Further, one of the Founders:

[F]lew to Washington, and I got on the net, I mean, we did what the two of us together, [...aside...], we did what the two of us do, that, um, she's the good public spokesperson, and I'm the good behind-the-scenes researcher. I know the Internet. So, um, officially, I just put the word out on our Yahoo and Facebook page. That the legislation was going to cause these problems. I mean, can you imagine how much, first of all, families that have to pay out-of-pocket just to travel, insurance companies would have to pay every single month instead of once a quarter... It's going to be impossible. So it was going to deny children medical care. So, we rallied that kind of information together. We had 7,000 phone calls hit Washington D.C. Monday morning. When [name] walked in the door, they actually asked her to have her people stop calling. And that's just not heard of in D.C. We were able to stop a legislation that was a guaranteed go. Within 48 hours. Just us. And you see us. It's not like were a football stadium full of people. (*MAGIC Interview #2*)

This description plays to the organization's strengths, one of which is having parents who are willing to act on behalf of the Foundation.⁴⁹

Fundraising

Funding for the organization comes from three main avenues; membership fees and dues, fundraising, both at the organizational and the individual level, and from corporate sponsorship, primarily from the pharmaceuticals. One source of funding is the

⁴⁹ "So we fight for the average kind of person. And when you put the power of that many people together in one place, that are doing it for the right reasons, there's a passion behind it that can't be shut down. And that's, I think, our strength" (*MAGIC Interview #2*).

parents that hold their own fundraisers. One mother, who joined MAGIC in 2007, has held a walk every year. In 2007, 39 people took part and \$3,300 was raised. In 2008, 110 people took part and over \$10,000 was raised. In 2009, 149 people took part and \$13,500 was raised. And in 2010, 125 people took part and \$18,500 was raised. Another mother raised \$20,000 on her own. There are also smaller fundraisers like bake sales, which also contribute money to the Foundation.

While the staff of the organization is made up of only four people, the families seem to have a strong preference for volunteerism, and many are willing to help in any way they can because of what they perceive to be the benefits they have received from their membership in MAGIC. I heard the phrase “Whatever they need me to do,” more times than I could count from parents. I think this goes back to the organization being started by moms and being very parent-focused. It also has to do with the fact that many of the members who are mothers are also housewives, and have the time available to donate to the organization; the importance of their structural availability should not be underestimated (Snow, Zurcher, and Ekland-Olson 1980). The parents I talked to had run marathons, and had also done a variety of other things to help the organization, both by earning money and on a volunteer basis.

This ethic of volunteerism and giving back is not lost on the Founders of the Foundation. In fact, they feel that the parent-centered nature of the workings of the Foundation is what propels member families forward, toward not only giving back to the Foundation, but for spreading the word outside of the Foundation, as well: “[O]ur parents are out there and they’re putting stuff out there. ‘Go to MAGIC, go to MAGIC, go to MAGIC.’ And they’re not doing it because their goal is to promote the Foundation.

They're doing it because they found something of value from us. It's because we're parent-driven" (*MAGIC Interview #2*).

Pharmaceutical Companies

Although MAGIC leaders emphasize the role of parents in fundraising, in fact the organization actively seeks corporate sponsorship; a major source of funding for the organization comes from corporate sponsorship, and the main source is the pharmaceutical companies that produce growth hormone. As described at the beginning of this chapter, the pharmaceutical companies set up shop during the "exhibit" portion of the conference, which is the only event that takes place on the first evening of the conference.

It is difficult to observe the pharmaceuticals at the conference without concluding that they are marketing their products. However, the leadership of the organization denies that the pharmaceutical companies are there to sell products.⁵⁰ As one of the Founders explained:

Which people say, 'Oh yeah, well they're just, they're just, um, helping, um, make more money.' Well, they're not. You know, any dime that they help us with, just helps the kids that are actually on their product. It's not like they're making a profit off of it. When they come here, they're not making a dime. All these kids are already on drugs. It's not like they're going to get a new patient out of it...But they're not promoting their drugs...They're actually trying to help entertain the kids. But they do have someone there with medical knowledge about their product that can answer questions because, as you see, there're families with all, they all use different kinds of drugs.⁵¹ And that's the product. And we're not here to point them to one drug or another. We're just here to say, 'Okay, if you're

⁵⁰ One of the Founders suggested that I ask the following question to pharmaceutical company representatives: "Why do you spend money that you don't need to spend to come to something that's not really profitable for you?" Unfortunately, I was never able to get the opportunity to answer this question or to ascertain the relationship between the organization and the pharmaceutical companies, from the pharmaceutical perspective, because I was rebuffed. Again, company representatives had no problem giving me the hard sell about their products, but would not divulge the nature of their relationship to MAGIC.

⁵¹ It is interesting that while the organization's leaders maintain that growth hormone is a naturally occurring substance of the body, they refer to it as a drug.

having problems with your injection device, there's [sic] some people that know how these things are supposed to work. Go talk to them.' And while, in the meantime, the kids are playing video games and climbing the walls, you know, literally. So it's not a promotional front. They know, like I said earlier, every single kid here is already on a product. So their goal is not to sell them. Their goal is strictly to support them. And if congress does something to mess that up, I'm going to be really upset. Because this is one of the few times that they [the pharmaceutical companies] can actually be honestly and completely philanthropic. They're not asking for anything in return, they're not expecting anything, they're truly just coming to give the kids some joy and help the parents if they need it. (*MAGIC Interview #2*)

One reason that the organization may describe the event in these terms concerns the criticism organizations such as MAGIC have received for allowing the pharmaceutical companies to be involved to the degree that they are.⁵² And Carl Elliott's (2010) depiction of the pharmaceutical industry as being completely money-driven does not fill us with confidence that these companies are involved with MAGIC for altruistic reasons. *They are there to sell products.*

Even if it is the case, that the presence of the pharmaceutical companies at the conference is not to make money explicitly, they already have done so, because MAGIC has encouraged parents to take their children to doctors in order to have their short stature treated, mainly via the use of growth hormone therapy. The presence of these companies, therefore, suggests that they are well aware that parent-members of MAGIC are key money-makers for them in the long run.

MAGIC espouses the view that they have the best interests of the children at heart, while also claiming that the pharmaceutical companies feel the same way. So trying to frame their involvement with the pharmaceuticals so as to move the focus off of selling and onto the kids makes logical sense since it provides a narrative that legitimizes

⁵² Significantly, the badge given out to participants at MAGIC largely proclaimed "Lilly" (as in Eli Lilly, the pharmaceutical company), while the badge given out at LPA only had the name of the organization on it.

both MAGIC and the pharmaceuticals. Also, it is common for advocacy groups to take advantage of what pharmaceutical companies have to offer, since these organizations tend to be strapped for cash and are happy to oblige with a little direct-to-consumer advertising if it means more money for the organization (Conrad 2005; Elliott 2010). The relationship between MAGIC and the pharmaceutical companies is symbiotic, since both organizations use the other to serve their own purposes.

Complications: Parental and Other Views of the Organization

*Profit Versus Altruism: The Role of Pharmaceutical Companies*⁵³

Despite the contention of its leaders that the pharmaceuticals are concerned with providing a service, rather than with profits, my own observations suggest that the pharmaceutical companies were there to sell their products. I certainly received a sales pitch at every booth I walked up to. I got so much information about each brand of growth hormone, plus free swag. Just as pharmaceutical companies used to “sex up” drugs for doctors with extravagant giveaways, at the MAGIC conference, pharmaceutical companies sell drugs in another way. They display their products for parents to see and demonstrate, with messages about “kid-friendliness.” They also have free stuff and activities for the kids.

In recent years, we have seen a move from drug representatives scouting out doctors’ offices to pharmaceutical companies capitalizing on direct-to-consumer advertising (Conrad 2005; Elliott 2010). While direct-to-consumer advertising has most commonly taken place on TV and the radio (Elliott 2010), growth hormone has not been widely advertised in this manner. This may be because parents are already socialized to

⁵³ Wilma’s son had a problem with one of the preservatives and was switched to a different growth hormone. Because of this, unlike most families, her son does not use one of the fancy injection pens, but rather, the “old fashioned” bottle and syringe application.

be concerned if their child is small. They seek out doctors who then provide them with information about drugs. It is also due, in part, to organizations like MAGIC, which fuel the fire of parental worry and concern, and leads parents to seek out a diagnosis and treatment. In other words, these companies do not have to do an onslaught of mainstream advertising because of the built-in stream of consumers they gain from organizations like MAGIC.

Framing and marketing are similar activities: Just as MAGIC's leaders craft a legitimizing public narrative that emphasizes health, designed to win over a public skeptical of enhancements, so do the pharmaceuticals package growth hormone to win over a market. As described above, with free giveaways and promises of "kid-friendliness," it is clear that the key demographic that the pharmaceutical companies are catering to is MAGIC parents. One can see in the promotional materials, both in hard copy and online, from the pharmaceutical companies that produce growth hormone, an ethic of selling that utilizes "kid-friendly" propaganda to attract parents (such as changeable "skins" for injection pens, similar to those used on laptops and cell phones). According to Pfizer (2008), in regard to its growth hormone Genotropin, "Before long, the injection will be just a routine part of their day. Like brushing their teeth – it's just something to do each day". Further, "Try the NEW GENOTROPIN Growth Tracker at GENOTROPIN.com!...A great new tool to track your child's growth potential...Start tracking your child's growth potential today at GENOTROPIN.com!" (Pfizer 2011).

The promotional materials for Tev-Tropin include the following slogan: "His dreams are bigger than his body...For now" (Teva Pharmaceuticals USA 2008). The company provides a "Welcome Backpack Kit" to new patients, which includes a

backpack, DVD, cooler, growth chart, patient instruction brochure, injection log, and zipper pull. The zipper pull is described: “[I]n the shape of a space rocket is a reminder that your patient is about to take off to new heights” (Teva Pharmaceuticals USA 2008). The growth chart “can be hung on the door frame and can be easily removed and repositioned. Now you can take your child’s growth chart with you if you move” (Teva Pharmaceuticals USA 2008)!

This company also has its own device, the TJet, which uses special technology to inject without using a needle. The brochure for the device espouses it as “kid-friendly,” and suggests that “With the TJet device, worrying about needles is pointless” (Teva Pharmaceuticals USA 2010). On the opening page of the company’s website, it says, “He’s a real grow-getter with the power of Tev-Tropin” and further into the website, it says, “Luckily there is something that can help kids reach new heights. Growth hormone replacement therapy with Tev-Tropin helps get kids growing” (Teva Pharmaceuticals USA 2012).

With the cute word plays about growth, it is clear that not only is the company espousing “kid-friendly” products, but further, products that will entice parents to pick a certain pharmaceutical company over another. There’s nothing like a healthy dose of competition to fuel the fire. Furthermore, as we can see from the advertising of growth hormone, that unlike MAGIC’s leaders, pharmaceutical companies are in no way espousing health. For them, it is all about growth, both in inches and dollars.

There is also a video which attempts to explain how the TJet works with the Quick Start TJet Guide. Imagine this being said by a Gumby-esque, red figure with a British accent:

Hi there, my name is Teddy. And just like you, my doctor told me I need to have a special medicine called growth hormone. And I think I was really lucky. I've been given a cool TJet to help with giving my medication. Just stay there for two minutes and I'll show you how it works. There's someone I want you to meet. Come on, don't be shy. Yay! It's my good friend TJ. Hey TJ! High five! Come and say hi to my new friends. Now, it's time to get started. Where's that little glass bottle with the growth hormone in it? The one we got ready earlier. That's it! Wow! It's nice and cold. Okay. All you have to do is take the top off the bottle, put TJ here. Are you on there nice and tight? Okay, TJ, on your head. Over you go! Is that okay for you, TJ? Now, when you saw your doctor or nurse, they gave you a special number. They call this the dose, but I call it my secret code. You can too, if you like. TJ, show everyone where they need to put their secret code number. This'll make you laugh. Guess how we make the code number appear? You'll never believe it. We twist TJ's head around 'til the right number appears. Don't worry, it doesn't hurt him, does it TJ? Don't worry if you go past the number you want. If you do, just wind back until you get it right. When you're happy with your number, make sure there are no air bubbles. And don't forget to put the growth hormone back in the fridge. TJ, show them where your safety switch is. This is in the locked position so that it can't be given by mistake. Can you see it? Good. Now make sure you slide the switch to the unlocked position, like this. We're almost there. Decide where you want TJ to give you the growth hormone. Today, I've chosen here, on the top of my leg. Your nurse or doctor will have shown you the best places. Don't forget, it doesn't matter if TJ is upright or sideways. But you must hold it straight against your skin. Make sure that TJ is pressing nice and firmly against your skin, and press the orange button on TJ's head. Now listen for the click. This is when you know that you're growth hormone has been given. That's it! You're done! All you've got to do is wind TJ's head until you hear the click, and back again in the other direction, so that your secret code number goes back to 0.00. Make sure TJ goes back in his pouch until the next time, not in the fridge. Okay TJ, back to your pouch. I've got a skateboard waiting outside. Bye! (Teva Pharmaceuticals USA 2012; transcribed by the author)

This kid-friendly marketing is a ploy on the part of the pharmaceutical companies in an effort to sell their products to the parents of children with short stature. However, the previous passage suggests another audience: The children themselves, who (in the case of older children), give themselves injections, or who get daily injections from their parents. The description is designed to assuage the potential guilt of parents who have to administer the injections, and the fears of both parents and children, and to convince them that the daily injections are easy, quick and painless – almost fun. Absent from the

description is any mention of pain or discomfort. Elliott's (2010) description of the interaction between pharmaceutical company representatives and doctors is apt for the case of MAGIC: "And if by accident, the real purpose of the exchange is revealed, the result is like an elaborate theatrical dance in which the masks and costumes suddenly drop off and the actors come face to face with one another as they really are. Nobody wants to see that happen" (64-65).

In a way, parents become "small cogs in a vast health-care machine" (Elliott 2010: 72). In some ways, parents are proxies for their children, knowingly or unknowingly, offering their children up as pawns in the pharmaceutical companies' competitive game. While parents have what they believe to be the best interests of their children at heart, both pharmaceutical companies and the industry, as a whole, are businesses bent on making money as the primary purpose.

Also downplayed or de-emphasized, or rather, not even mentioned at all, in the exhibits is a discussion of parents' worst fears: The potential side-effects of growth hormone. One of the Founders explained:

And that's what the parents want to know. What caused their kid to have these problems? And they want to make sure that it's safe. And the only way to know that it's safe is to stay around, and hang around long enough, and keep up to date with it, so you know that you made a good decision... So we're the first. [name]'s kids, her son, my daughter, we're the first. So our kids are the first. So until they can meet our kids, they say, 'Okay. Well, they're alright. It'll be okay.' (*MAGIC Interview #2*)

While this is a real fear for parents, those fears are not specifically addressed by the pharmaceutical companies, most likely for fear that such information may change parents' minds, and they may opt not to treat their children with growth hormone at all.

Also absent from the exhibits – even the “small print” – is a discussion of another fact: Growth hormone has not been around long enough yet to know for sure all of the potential problems and side effects that can occur. It is not just a matter of parents meeting the children of the Founders of MAGIC for confirmation – as is suggested in the quote above – that they are doing the right thing. As recently as 2011, it has been reported that while growth hormone is relatively safe while it is being given, there have not been enough large-scale retrospective studies to provide valid conclusions about the safety of growth hormone in the long-term, especially in children that have Idiopathic Short Stature (Kemp and Frindik 2011).⁵⁴ I talked to many parents who were concerned about side effects and future implications of their children being on growth hormone. But whether it is because the organization is so persuasive or parents truly believe in their convictions, their fears are not so intense that they opt not to treat their children.⁵⁵

Health Versus Height: How Parents Frame the Issue

When Amanda shared her son’s story in a networking session, and described him as now being 5’9”, the room broke into spontaneous applause. This happened another time, when one of the Founders described her son as 5’7” and married, with two children.

⁵⁴ Most children treated with growth hormone are not tracked after they are finished with treatment, although there is disagreement, both in the general public and within the organization, about whether children with Growth Hormone Deficiency should receive maintenance doses of growth hormone into and throughout adulthood.

⁵⁵ As for the medical experts that take part in the conference, one of the Founders explained: “So, every single physician that’s here, is here on their own dime. One of them, as a matter of fact, has to take vacation because the university he works for would not allow him time off to be at seminars and symposiums. So, and he’s done it for 20 years. So they are not compensated; we cover their flight, and they have to use advance, 21-day, non-refundable, um, we pay their cab here, which is already pre-set-up, and we pay their hotel. They pay their own food, except for the meetings and one lunch that we pay for, and everything else they cover their own. They lose time away from the office, they can’t bill patients. I mean, they’re losing money to come here. Because they believe in what we’re doing is such a right thing to do, that they offer to do it. Now most other organizations don’t have that. They actually have to compensate the speakers. We don’t do it. We never have, and I don’t think we’ll ever have to. Which is a nice thing; that we, they think of us as being that ethical that they go above and beyond to help us out.” (*MAGIC Interview #2*)

It is hard to deny that what was being applauded was the increase in height to the “normal” range, and not the resolution of some type of health issue.

As suggested earlier, the leadership of the organization tries to emphasize the importance of growth as a measure of physical health, rather than as merely a psychosocial issue. But this “growth as a proxy for health” idea does not permeate all levels of membership; it does not extend far beyond the leaders of the organization. The parents whom I spoke with, by and large – unless their child had a life-threatening condition – spoke of wanting to help their child fit in, and were overjoyed when their child, who had not grown much previously, began to grow after being put on growth hormone. One mother said of the goals of the organization:

To make sure these kids who need growth hormone get it. From what I’ve read, and talking to [name] and [name] and [name], all, you know, they fought these battles with their own kid and their own children, that just amazed me, and they’re trying to help the rest of us. To give us information that we need, because it is a strange thing, finding out your child isn’t going to grow. (Bonnie and Jake; MAGIC Interview #3)

This mother’s concern is clearly about height, and not about health. But this is where the waters get muddied. The health versus height rhetoric is one that creates doubt about the cohesiveness of the organization, its goals and mission, and the goals and mission of its members. It seems that for parents, a concern for health comes into play when their decision to have their child treated with GH is questioned by others.

Tracy’s daughter fell off of the growth charts at age three, and they were sent to an endocrinologist when her daughter was five. At this time, an abscess was found on her daughter’s kidney, and her internal organs were being crushed because there was not enough room for them. After a week stint in the hospital, and receiving a second opinion, her daughter was diagnosed as a late bloomer with ISS. As Tracy explained:

[H]er original height was supposed to be 4'6", which would have been fine if she had been healthy. Um, I told her I would have loved her if she was Thumbelina. It didn't matter. So how she looks doesn't matter to me. I just want her to be healthy and have a productive life...I actually had a friend approach me and say 'I can't believe you're ashamed of your daughter's size and you would inject her twice a day just to make her taller.' I was like, 'Excuse me? It has nothing to do with size. It has to do with her health.' (Tracy; *MAGIC Interview #6*)

Recall that the leaders emphasized that they wanted to attract the parents of children with true growth disorders, rather than those merely concerned with making their children taller. However, many parents in MAGIC had children who were diagnosed with Idiopathic Short Stature, which was originally considered an off-label use of growth hormone and was not approved as an indication for treatment with GH by the Food and Drug Administration (FDA) until 2003. There are two, competing views of ISS: Short but normal (Gill 2006) and short due to unknown etiology (Wit, et al. 2008). The difference here is that one is saying simply short, and the other is saying short, due to a cause that is not yet known. Although some have suggested that the diagnostic evidence for a diagnosis of Growth Hormone Deficiency is arbitrary (Wit, et al. 2008), only GHD is a condition that can be diagnosed using laboratory studies (Louvel, et al. 2009). It is interesting that children with ISS and GHD are grouped together for the purposes of the organization. This seems to add legitimacy to ISS, which is often a controversial diagnosis (Gill 2006). It appears that along with the organization, parents also conflated the two diagnoses, at least in terms of ISS parents viewing their children as basically the same as children diagnosed with GHD. However, both GHD and ISS parents distinguished between their children and those with more serious diagnoses, those they deemed to be "truly" sick.⁵⁶

⁵⁶ In his study of families of children with polio, Davis (1963) describes the concept of "relative deprivation," of which he suggests that parents of children with polio feel deprived compared to the parents

Of her daughter, Tracy said, “Our daughter, um, could have had a lifetime of trouble...and, um, she possibly could have lost a kidney or two. You know? One or both. Then there are kids who are here, and they’re really sick” (Tracy; *MAGIC Interview #6*). Another mother said, “I mean, honestly, I have to tell you, my daughter gets a shot everyday. That’s it. One shot a day. There are kids here that are injected a whole lot more than that everyday, and if you put it in perspective, I mean, there are kids worse off than the kids here. So you kind of have to keep it in perspective” (Judy; *MAGIC Interview #9*). Here are two mothers, who in their interviews espoused the medical necessity of growth hormone for both of their daughters. And yet, here they are, also suggesting that the experience their child has had is not as serious as others in the organization. Both of these women are mothers of daughters diagnosed with ISS, which leads one to wonder if parental guilt is being assuaged by acknowledging that there are more serious conditions in the organization than those that simply cause short stature. In other words, by comparing their ISS daughters to children in the organization who are “truly sick,” these mothers further attempt to normalize the experience of growth hormone treatment for their children; their children get a shot a day, whereas some children in the organization suffer from disorders that cause physical and mental issues that last their entire lives.

Whose Stigma?

While there was talk above about the children being made to feel normal, at the organizational level, it seems that an unintended consequence of normalization is not just to make the child feel normal, but to make parents feel normal, as well. If Goffman is

of healthy children, but compared to families of children with polio who end up in an iron-lung or dead, parents with children who do not suffer that fate from polio feel fortunate. The same can be seen here with parents of children with Idiopathic Short Stature or Growth Hormone Deficiency feeling fortunate when compared to MAGIC parents whose children have more severe diagnoses.

correct, it is possible that parents feel a courtesy stigma as a result of their child's short stature (Goffman 1963: 31). Wilma, who attended the conference alone, without her husband and son, said:

Um, more than anything, it's a community full of resources. I've never met another family that has a child with a Growth Hormone Deficiency. I feel completely alone. So to be here at this convention, with hundreds of parents and families who have kids just like mine, it's liberating. And, um, just having doctors from all over the country come speak, and hear, you know, hear all about it, it's wonderful. It's the biggest resource. (Wilma; *MAGIC Interview #7*)

Another mother said similarly, "And, the thought about MAGIC is that it's a big family...I think the main goals are to educate parents, um, it's really the most important thing. I mean, I tell parents everyday, educate yourself and trust your instincts. Um, and for parents to feel like they're not alone. For them to have this community support, because some of these things are very, very overwhelming" (Judy; *MAGIC Interview #9*). Clearly, in the minds of parents, MAGIC is there to help them in a variety of different ways. Therefore, it is not surprising that when looking at experiences with growth hormone, what is being done to serve the parent and the child are difficult to distinguish. This type of normalization may seem at first glance to mirror the sense of normalcy I observed in LPA. However, it is important to remember that the need to normalize through growth hormone grows out of a sense that short stature is abnormal in the first place and may be further de-normalized as a result of treatment.

The lives of MAGIC families, who have children diagnosed with Idiopathic Short Stature or Growth Hormone Deficiency, are filled with growth charts, and parental self-blame.⁵⁷ And the story of how children end up on growth hormone was very similar across most of the families I spoke with at MAGIC. Usually concern is brought about a

⁵⁷ See earlier discussion in this chapter regarding parental guilt.

child's growth by the doctor, the parents, the child, or a combination, but most often, it is the parents that bring height (or lack thereof) to the attention of doctors. According to parents, most of their children are "normal" in terms of weight and length at birth, and then they begin to fall off the growth charts when they are between several months and a few years old. However, Marissa's daughter was born at 25-weeks, weighed one pound, seven ounces, and was considered a "micro-premie." Marissa, although she is 4'10" herself (although her husband is 5'11"), was told that treatments her daughter received early in life had the potential to stunt her growth. While she took her daughter to an endocrinologist at the age of five, it was not until her daughter was severely bullied in fourth grade that she became very proactive and started exploring her options.⁵⁸

Many parents talked about having to doctor shop, and having a long road to get to the proper specialist and the correct diagnosis for their child. One mother, Judy, described how she sought help for her child:

Judy: And that was, and the doctor didn't really listen. So after I left, I called her back, and I was like, you know, 'I'm still really concerned about it,' and she said, 'you're fine, don't rush, but you can bring her in a month or two, and have her re-weighed and measured if you want.' Um, at that point, I switched pediatricians. Because I felt like my concerns weren't being taken seriously. Um, so I took her to a pediatrician at that point my other daughter saw. Um, previously. And, um, told her my concerns. And she ran some initial blood work to check her thyroid, she checked her, um, glucose levels, and checked for normal CBC stuff to make sure she didn't have anything like leukemia or anything horrible. Um, and she came back and said, 'everything's normal, and so that's a good thing. So that tells us that things are probably okay. And so, bring her in every month, and weigh and measure her, and if she still isn't growing by two, we'll send you to a specialist.' And so, from 17 months to two [years of age], they wanted me just to wait and bring her in. And that's not really my personality. [laughs] Um, I just felt like I don't know what I'm waiting for. Like she hasn't grown in all this time. And

⁵⁸ Children are usually diagnosed with either Idiopathic Short Stature or a Growth Hormone Deficiency via a stimulation test to test hormone levels in the blood and/or an MRI in order to determine bone age. The stimulation test is used to measure the level of growth hormone in the blood after being given a medication used to trigger the release of GH. This typically involves an IV and multiple blood draws.

she's off the charts at this point. Um, so I researched endocrinologists in my area, and I wish I knew about MAGIC at that point, because I researched doctors in Maryland, Virginia, D.C., Delaware, Pennsylvania... So I found two doctors that I was interested in. And I got ahold of one of them... So, um, so at that point, we went to all these other specialists, got a bunch of things ruled out. And then came back, right after she was two, had a stimulation test, and got diagnosed [with Growth Hormone Deficiency]. (Judy; *MAGIC Interview #9*)

Other parents described similar experiences:

Wilma: My son is [son's name]. And he's six. Um, he grew normally as a baby, and then kind of, at about age two, he started to stop [growing]. And the pediatrician became concerned and referred us to the endocrinologist. And um, it took several doctors, and two years, two and a half years, but we finally found out that he had a deficiency. They did the stimulation test, and he failed both of them. And an MRI showed that he has a teeny-tiny pituitary gland. It's healthy, it's normal, but it couldn't pump out enough growth hormone. By the time he got to two, it couldn't keep up. So he stopped growing and fell way below the growth chart. So he started the growth hormone when he was four and a half. He's been on it for two years, and is now in the twelfth percentile. He was off the chart for three years. It's working, and he tolerates everything very well. And he hasn't had any problems with it. (*MAGIC Interview #7*)

Tracy: Um, well, my daughter [name], or our daughter [name], when she was three years old, fell off the growth chart. And so her pediatrician started keeping an eye on her. And when she was five, he sent her to an endocrinologist. And the endo said, um, 'I just need to observe her for a couple, you know, like a year or two'... When she was in kindergarten, she was five, she wore a size 2T [toddler size]. So, and, and that was at a Catholic school. So she had to have her uniform tailored, because it was still too big. And she had trouble like opening doors, because they were too heavy, and she couldn't reach the drinking fountain, that type of thing. And, um, because she was just being observed, we never got on the growth charts. (*MAGIC Interview #6*)

Bonnie: I remember asking Doctor [name], 'Do we need to go see the endocrinologist?' Because I knew that one. And he told me, very gutsy, 'Well, there may be a problem, but the endocrinologist will not see children for a possible growth disorder until the child is at least nine or 10 years old.' I didn't know any better. And I didn't know about MAGIC. So as I, I watched my son get farther and farther behind his classmates. So I watched, he played baseball and football since he was [aside to son: When did you start?] in kindergarten or first grade. And I watched him fall farther and farther behind. You know, we could see in his kindergarten year, there was a noticeable height difference. (*MAGIC Interview #3*)

And this was one source of parental guilt. Many of the parents I talked to said they should have pushed pediatricians harder, should have advocated for treatment earlier. But when it comes to doctors, parents tend to trust what they are told because they have no other choice. While some parents worry about the potential side effects of the treatments that their children receive, more often, their primary concern is guilt about not having been more aggressive about finding treatment earlier. A common thread among all stories is that parents noticed a problem in their child and were highly motivated in finding a solution. Another common thread is that parental concerns were diminished because at least one parent was considered to be of short stature. Parents went to pediatricians expressing their concern about their child not growing or being the shortest in their class, and doctors often dismissed these fears, saying the child would grow, or that because parents were short, so they would expect the child to be short, as well.

Doctors tended to normalize short stature longer than parents, but this actually contributed to parental concern, rather than alleviating it. And it often resulted in parents attempting to find a new doctor or forced them to go doctor shopping until they found a doctor who told them what they wanted to hear, and was equally motivated in finding the cause of their child's short stature and a solution for it. Unlike parents of children who are diagnosed with a severe illness, such as polio or cancer, who seek a second opinion to make sure the diagnosis is correct – in the hopes that it is not and is something less severe – MAGIC parents will keep going to doctors until they obtain a diagnosis for their children (Davis 1963). As mentioned above, however, while parents actively, and sometimes relentlessly, sought out a diagnosis for their child's short stature, they were relieved that their child did not have something more serious.

Others, such as Schneider and Conrad (1983), in their study of epilepsy, and Davis (1963), in his study of polio victims, have suggested that normalization is a key strategy in making sense of illness processes, and the accompanying stigma. In many ways, MAGIC embodies a traditional mode of dealing with illness, in which it follows that one identifies symptoms and then seeks medical help (Schneider and Conrad 1983). In some ways, however, many MAGIC parents behave in the opposite way, and seek a diagnosis and then attribute a cause.

Amanda described of her now grown son:

So the pediatrician was only looking back 18 months behind [son's name]'s chronological age. And he said, um, now he has a little growth delay, a Constitutional Growth Delay. And basically he'll be a late bloomer, or that he would grow to be a normal height, but just later than his peers. And, in terms of my family, we have tall people in the family and we have short people in the family, you know, and we have, um, you know, several relatives, including ourselves, who were on the later end of normal, as far as hitting puberty and developing like that. So we just figured that [son's name] was just taking after our family. And we didn't push it anymore. And I'm worried that we shouldn't be pushing it anymore. So we just waited for nature to take care of it, and [son's name] was at the point where he was starting to get bullied, you know, because kids, you know, any difference... So by 10, you know, I always thought, you know, again, this is my lack of knowledge, that if he had any growth, that, that was good. And, um, I didn't realize that he was supposed to be growing two to two-and-a-half inches a year, which he wasn't. And he was falling lower and lower on the growth curve, but our pediatrician kept saying, 'No, he's just, he's a late developer. Don't worry.' And the other thing is, my husband's 5'5". I'm three inches taller than my husband. And these, a lot of conditions, if you have one shorter person... You know, I tried to do as much as I could. You know, he was getting more and more impatient about not growing, and I kept saying, 'Well, we just have to wait for nature to kick in.' Because I didn't know that there was something there... Another thing that I didn't know at the time is that Constitutional Growth Delay is a diagnosis of exclusion. It's not supposed to be the first line diagnosis. And the pediatrician again said to us that he thought it was CGD [Constitutional Growth Delay]. Um, and [son's name] for the first time, having tears, about how upset he was being short, that he wanted to grow, and all that. And our pediatrician, at that point, sent us to the endocrinologist, again telling us everything was fine, but she felt that if [son's name] was sent to a specialist, that he may be more comforting to [son's name], and that he would be more comfortable waiting for nature to kick in... Um, so the next test that they

did, of course, was, um, was the stimulation test... it's supposed to be above 10, and [son's name]'s peak was a 3.1... And so from that moment, I thought, okay, he needs growth hormone. (Amanda; *MAGIC Interview #8*)

One has to wonder if it was finally the son articulating that his height bothered him that prompted the referral to the endocrinologist. One also has to wonder how parental concern influences the child's own feelings about his or her height. Because of the young age of most of these children, parents are the key arbiters of explanations about short stature, illness, and treatment.

While Amanda describes her son's unhappiness with his height, it is difficult to distinguish whether parents who go to doctors and ultimately treat their children with growth hormone are speaking for their child's qualms about their height, or for their own qualms about their child's height, or a combination of both.

Further she said:

So, at the time, it seemed excruciatingly slow, like we were taking baby steps... And um, in hindsight, you know... now I don't have [*sic*] whether or not he needed it. You know, he definitely needed it. You know, the only thing that I feel bad in hindsight is that I didn't have the information I have now, because, you know, if I had this back when he was seven, I could have spared him years of torture, you know, from the other kids at all, I would have done that. [long pause] But because of that experience, anything that I can do to help others to not have to walk down the same path, that's what motivates me. (Amanda; *MAGIC Interview #8*)

Here Amanda describes why she became actively involved in MAGIC even though she found out about the organization and joined long after her son was done receiving treatment with GH. She too has guilt over the lengthiness of the process, and pledged to help other families avoid having a similar experience to the one she had. It should be noted, however, that even today, many parents talked about it taking years of doctors' visits and testing to actually get a diagnosis for their child.

Most parents recounted the “amazing” results they had seen once their child was on growth hormone.^{59,60} Marissa’s daughter, who was diagnosed with Idiopathic Short Stature, grew four inches the first year she was on growth hormone. Another mother said:

And I won’t bore you with all the details, but he’s grown, in the first year, he’s grown the pretty much standard four inches. In the first year. He’s done very well with it. He’s, we’re eight months into the second year of treatment, and his growth velocity has slowed a little bit, but again, that’s pretty much the way they say it’s supposed to be. He’s had no adverse reactions, other than he eats everything in sight now. He is obviously, he was well-proportioned, he was not thin, even before he was solid, but I believe he is even more so now. His exercise tolerance is better. He was always running before, and it’s more so... Two years ago, when he started playing on the team in the baseball league, it was very evident. [Talking to son: Everybody was, some over a head taller than you are.] Last year, um, not quite as much, but still you could tell which [son’s name] was, and of course of the rest of the team. This year, we had to look and figure out where he was by number... Or by position. So if there’s the team, there’s the shortest one, there’s [son’s name]. So that, that’s been good. To me, the thing that’s not that often is like, oh, there’s [son’s name], he’s the shortest one on the team. (Bonnie and Jake; *MAGIC Interview #3*)

Along with emphasizing the positive results that her son has had from growth hormone, this mother also illustrates how parental concern about short stature is at the forefront of treatment decisions.

In the case of such young children, clearly the concern about height stems more firmly from the parents than the child. While there was a significant amount of parental guilt around finding a doctor that was willing to treat their child, interestingly enough, most did not have a significant amount of guilt about having to give their young children injections. As Wilma described her young son:

⁵⁹ Even amongst MAGIC doctors, positive results are touted. In fact, one doctor said, “If you give a rock growth hormone, it will grow,” suggesting that not only is growth hormone a miracle drug, but it should and does work in all cases. Within the Foundation, you do not hear the stories of those who have not had “miraculous” results from growth hormone. As I and others have stated elsewhere (Conrad & Leiter, 2004; Conrad & Potter, 2004; Cutler, 2004; Rott 2010; Voss, 2000), most of those treated with growth hormone only gain a few inches in height; rarely enough to make them equal in stature to their average height peers.

⁶⁰ Moreover, I did not hear stories of those children who could not tolerate any brand of growth hormone, or those who could not stand the physical and emotional stress of daily injections.

No. He was starting to ask a lot of questions. You know, what they were, why two-year-olds were bigger than he is. You know, and we started talking to him about it. And once he could, we kind of had to bracket that something was going on, and he didn't exactly realize that it was about growth. And we said, 'Yeah. You know, once you start the medicine, you could get much bigger.' And I said, 'Yeah.' And explained to him that it was a shot...And he was totally fine. He's never had a problem. Never shed a tear. We've never had to pin him down, fight him. It's been really easy (Judy; *MAGIC Interview #9*).

As I noted in the first chapter, I came to this study with the position of being a woman of short stature who was not treated with growth hormone as a child, and therefore have a negative view of enhancement. Just as short stature is medicalized by parents, doctors, and MAGIC, it is the atmosphere of MAGIC, of meeting other families who give their children multiple shots a week, which celebrates the potentially normalizing effect that growth hormone will have on children who are of short stature.

Treatment with growth hormone for children with Idiopathic Short Stature or Growth Hormone Deficiency typically occurs on a daily basis until puberty. However, some parents opt to use other hormones to delay puberty so that their children will have a longer period in which they are able to grow. One mother I spoke with told me that her daughter was on Lupron,⁶¹ a drug that stops the onset of normal puberty. Another mother told me:

Well, they're going to keep her on it [growth hormone] until her bones fuse. Um, we have a [inaudible] implant, to stop puberty...So they had to do an implant in this year, to stop puberty. They would like to put another implant in, in December, to go another year. She's not so keen on that idea...That's basically what it is...they injected this little, like inch and a half long spaghetti noodle sized, you know, thing in her arm. And it slowly releases hormones, in her, it overstimulated her estrogen production. (Tracy; *MAGIC Interview #6*)

The commonality here is the notion that doctors tried to maximize the amount of time children stayed on growth hormone in order to gain the maximum amount of inches. This

⁶¹ Lupron is also used to treat Prostate Cancer in men, Endometriosis and Fibroids in women, and Central Precocious Puberty (CPP) in children (AbbVie, Inc. 2013).

quest for height, is, according to the leadership of the organization, not the goal of the organization. And yet, all of the ISS and GHD parents⁶² that I spoke with emphasized wanting their children not to be the smallest in the class, and a desire to put an end to the bullying that some short children received. And the mothers who put their children on hormones to delay puberty embody that desire, taken to the extreme.

For those who are members of MAGIC, extended limb lengthening is typically only used for children who have Russell-Silver Syndrome, or any other disorder, that causes a limb length discrepancy. The 2011 conference included an educational segment, the first ever held on limb lengthening. The rhetoric of that presentation was that children are not tortured by the experience of limb lengthening surgery, and that children are happy and even excited by treatment (which is known for being invasive and has a significant recovery time).

It was clear from the murmurs from the audience that limb lengthening surgery is a contentious topic, the source of disagreement and differences of opinion. The doctor who presented on limb lengthening went as far as to suggest “combination therapy,” using both treatment with growth hormone and extended limb lengthening surgery, as the best way to minimize limb length discrepancies and add inches to height.

When asked about what she knew about limb lengthening, one mother of a daughter with Idiopathic Short Stature said, “Yeah, that’s not true. That’s bad. When your bones fuse, you’re done growing. You’re done. You know? Sorry! You’re done! So, yes, I have heard people who think that’s true. And there may be places where they

⁶² As described earlier, ISS and GHD parents are combined at the conference, and this appeared to me to be the largest diagnostic group represented.

consider it, other countries where they will cut your shin in half and add a rod. Yes, I've heard of it" (Tracy; *MAGIC Interview #6*).

While this shows a lack of knowledge on the part of some parents – that limb lengthening, like growth hormone, can only be effective pre-puberty, which is not true in the case of limb lengthening – it also shows how the organization has bracketed enhancement technologies by illness type. This is to say that the organization has not, at least not yet, made limb lengthening surgery a common practice across the organization. It is currently only used in conditions where there is a limb length discrepancy, but as the doctor who presented on it suggested, limb lengthening surgery could find wider use among the short statured members of MAGIC who do not have limb length discrepancies.

Further, it shows the significant reliance that the Foundation places on growth hormone therapy, as opposed to other technologies. However, since 2011 was the first year that they ever had a presentation on limb lengthening, it is possible that they may be moving in that direction and expanding their acceptance of a variety of technologies used to enhance growth. It is entirely possible, however, that neither a shot a day nor an extreme surgery used to lengthen limbs, provide a prescription for children to feel better about themselves; rather, it provides a reminder that they are different, abnormal, or sick and unhealthy.

Conclusion

Despite the formal organizational structure of MAGIC (Staggenborg 1988), by closely observing the MAGIC Foundation, it becomes clear that the organization is a complicated one, in which several contradictions exist, the greatest being the difference

in opinion between the leadership, and its members and the pharmaceutical companies that play a large role in the organization (Taylor and Whittier 1992). The leaders focus on “height as a proxy for health,” whereas it seems that for parents and pharmaceuticals, the key concern is height alone. By framing the issue of short stature, and the subsequent use of growth hormone, as an issue of health rather than height, gives legitimacy not only to the MAGIC Foundation, itself, but also to those parents who have a concern about a child who is not growing. We live in a culture in which health is viewed as universally accepted, a normal state, whereas the sick are viewed as trying to evade social responsibility (Parsons 1951); and yet, we also live in a culture that expresses ambivalence toward the use of enhancement technologies, designed to make people “better than well” (Elliott 2003). And based on reactions from those outside of the organization, it is clear that there is a lack of public support for treating a short child with growth hormone solely for the sake of increasing height. The leadership of the organization is keenly aware of this fact, and therefore chooses to deflect attention off of height and onto health. This rhetoric allows the leadership of the organization to portray growth hormone as an essential component of health rather than being merely an enhancement to help children gain a competitive edge with a few extra inches. The health versus height dichotomy becomes a legitimating narrative for what the Foundation does.

While the health versus height rhetoric serves as a legitimating narrative for the leaders of the organization, the master frame of normalization is shared by all involved. The leaders feel that normalization is attained by pursuing health. For parents, normalization means attaining a “normal” appearance, so their children will no longer be the shortest in the class, will not be bullied, and will not be identified solely by their

height. The conference creates a sense of normality in which both children and their parents feel a sense that there are others like them and they are not alone. And George, who represents both health and height, is a powerful symbol because he represents both kinds of normalization. This dual sense of normalization is typified by, on the one hand, the need to make short children taller by treating them with growth hormone so they attain a “normal” height; and on the other hand, by medicalizing their short stature to a degree that elicits treatment very different from the everyday lives of average height children, bringing them into the organization so that they can be made to feel that such treatment is “normal”.

For MAGIC, normalization is achieved through the medicalization of height and the use of human growth hormone. Leaders assert that short stature is a symptom of greater disease. While parents are not as insistent on proving their children are “really sick,” they seek to treat their children’s short stature medically. MAGIC typifies a recent trend in medicalization, in which organized consumer groups have become one of the key “engines” of medicalization (Conrad 2005). More and more often, medical decision-making is being taken out of the hands of doctors and is being placed directly into the hands of consumers and pharmaceutical companies (Conrad 2005). This is clearly seen in the involvement of pharmaceutical companies within MAGIC, with company representatives interacting directly with parents and their children regarding their products. Conrad (2005) describes this tension well: “Spokespeople from such groups often take strong stances supporting pharmaceutical research and treatment, raising questions of where consumer advocates begin and pharmaceutical promotion ends. This reflects the power of corporations in shaping and co-opting advocacy groups” (9). This

raises the question of whether MAGIC and the pharmaceutical companies have commensurate goals. While the leaders of the organization suggest that they do, observations of pharmaceutical involvement within the organization suggests otherwise.

There is an inherent tension in using both the rhetoric of medicalization and normalization. On one hand, both the leaders of the organization and the parent members want their children to be “normal”. However, by medicalizing short stature as a disease to be treated, parents may in fact be giving their children a sense that they are sick or abnormal, drawing attention to their difference, rather than minimizing it. This is not just the case here, but as Conrad (1992) has noted, inherent in the more recent variety of medicalization is the idea of treating a phenomenon that was once seen as a difference into a disease or abnormality. Thus, medicalization may actually contribute to a feeling of being sick or abnormal, rather than alleviating it (Conrad 1992).

Constant doctors’ appointments, testing, and a regimen of daily injections can hardly make children feel “normal”. While it is true that some older children may be bullied or feel unhappy because of their short stature, and express this to their parents, younger children may learn from their parents that they “fall short” of normal expectations, rather than expressing their own insecurities about their size.

Further, the organization is implying – while suggesting that they do not support parents who merely want their child to be perfect, read tall – that if one has the money, and can run the gauntlet of the healthcare and insurance system, height is fully attainable. It’s clear that MAGIC parents want what is best for their children, and think that they are doing what is best for them by seeking out medical expertise. And the organizational ideology of MAGIC leads them on a path that involves the use of enhancement

technologies, to help normalize their children to “fit in” with their average height peers. If MAGIC succeeds, it will in all actuality make itself obsolete; but this is an unrealistic goal because there will always be a group of short children, when in fact, it is society’s view of these children – not the children themselves – who need to change. Other organizations have different aspirations and views of technology, as the next chapter, about the National Organization of Short Statured Adults (NOSSA), will show.

Chapter 4:

National Organization of Short Statured Adults (NOSSA)⁶³

Introduction

As of January 2013, the following message was posted on the homepage of the National Organization for Short Statured Adults website: “NOSSA will be ceasing operations and will no longer be accepting membership applications or donations. Questions may be directed to us through this website. Thank you!” (National Organization of Short Statured Adults, Inc., “Homepage”). When I read this message about the demise of NOSSA, my first thought was that my dissertation was finished, that I would not be able to complete it given that this organization – one of three I studied – no longer exists. After all, why would anyone be interested in hearing about an organization that no longer existed?

Adding to my disappointment was the fact that it had been difficult to find and locate the three active members of the organization that I had interviewed. All three (one male, two female) had served as Board members of the organization at one time or another. The male participant worked in a highly gendered field, and had experienced harassment and discrimination as a result of his short stature. Both female participants were professionals, and both described to me experiences they had, both when they were

⁶³ This may eventually be one of the only written records that NOSSA actually existed.

growing up, and as adults, in which their height (or lack thereof) was a particularly salient factor in their lives.

Moreover, of the three organizations, NOSSA's ideology was the most opposed to prejudice and discrimination on the basis of height. Unlike LPA, which utilized separatism, and MAGIC, which utilized normalization, NOSSA utilized assimilation and advocated for equal rights.⁶⁴ The fact that NOSSA's goals most clearly resonated with my own further fueled my disappointment.

However, I soon realized that NOSSA's demise raised several interesting sociological questions. Why did NOSSA fail when other organizations, some with similar goals, managed to endure? What elements of "successful" mobilization were lacking in NOSSA? Had NOSSA ever been a social movement in the first place? Ultimately, the end of NOSSA meant that my dissertation could answer a research question that had seemed unanswerable to this point: Why do some movements endure while others die? How do we come to understand the failure of mobilization, or negative cases, such as this one?

By describing and analyzing the organization in how it existed will allow us to be able to elucidate the reasons for why it ultimately failed. In this final data chapter, I will describe the organization, its goals and mission, and the organization's view of enhancement technologies. This description will provide background for the next section, in which I conduct a "social autopsy" (Klineberg 2002: 11), in which I will examine the sociological factors related to NOSSA's demise. By examining NOSSA's characteristics and comparing NOSSA to other organizations that shared common features, but which

⁶⁴ By assimilation, I mean wanting to be included in broader society, as social movement scholars have come to embrace the term (for example see Bernstein 2005), rather than the use of assimilation as in blending in, used by sociologists who do not study social movements.

had more “staying power”, we can understand the reasons for NOSSA’s failure, and by implication, why other social movements manage to endure.

What Was NOSSA?

NOSSA was an all-volunteer organization that was created in 2005 as an unincorporated organization, and it gained non-profit status in 2006. NOSSA functioned almost exclusively as an online entity that grew out of a website known as Short Persons Support (sPs), which was started in 2000 (Short Persons Support 2012). According to the Editor of the Short Persons Support website:

Short Persons Support is primarily a Web site library with a great deal of information collected for the past 11 years. NOSSA is an organization that provides a supportive environment in which to share experiences, oppose heightism⁶⁵ in society, and promote the message of self-empowerment for all of their members. sPs came first and a few years later NOSSA was formed to take the support to the next level... (S. Goldsmith, personal communication, August 14, 2011)

Of the move from Short Persons Support to NOSSA:

And it was, uh, the first of its kind, to talk about, um, the issues that I was dealing with. Um, which I thought I was alone. Because no one ever talked about, uh, you know, heightism or height discrimination, or anything like that. If it was discussed, it was, you know, laughed at. So the fact that I found this website that was devoted to it was like wow!... I decided to have a support group meeting... And, uh, you know, talk about this stuff and try and, you know, give each other support and encouragement, and uh, and that sort of thing... It was such a great feeling to finally be able to talk to people that felt the same way that I did about, um, being short, heightism, and height discrimination. (Mike; *NOSSA Interview #1*)

NOSSA sought to take the organization to the next level by trying to bring people together to create awareness about issues of short stature, in the form of in-person support groups and meet-ups. These groups were informal and met infrequently:

⁶⁵ NOSSA defines heightism as “a prejudiced attitude about human height that often results in discrimination. It is based on the belief that short stature is an inferior trait and therefore undesirable” (National Organization of Short Statured Adults, “Heightism”).

Um, what we do is, because of the, everybody being spread out, we try and encourage people to do things locally. Um, we're trying to bring together our members, so that they can start their own chapters, they can start their own support meetings, and that sort of thing. We haven't been as successful with that as we [*sic*] like, but that's something we're still continuing to pursue. (Mike; *NOSSA Interview #1*)

While the membership of the organization seems to have been constantly in flux, at its height it had about 300 members (Mike; *NOSSA Interview #1*). Funding for the organization came from membership dues of \$25 per person, per year. NOSSA defined short stature as being 5'7" and under for men and 5'4" and under for women. However, the organization tried to be inclusive: "We accept people of all heights. If a person is, let's say for instance 6'2", and they support our organization, they're certainly welcome to join our group... But as far as I know, we do not have any, uh, average height or tall people in the group" (Mike; *NOSSA Interview #1*).

NOSSA had several principal goals: Helping short people, themselves, in various aspects of life; helping to raise awareness about and combatting heightism and height discrimination; and helping change societal views of short stature. The main goal of NOSSA was: "To provide support for short statured people, and to educate the public about heightism and height discrimination" and to disseminate information via the Internet (Mike; *NOSSA Interview #1*). Again, while the organization did hold infrequent in-person support groups in the New York area, the main avenue for connecting members with each other was online; through forums, providing information, and "limited legal assistance with height discrimination claims" (Mike; *NOSSA Interview #1*).

Short Support

Creating a group feeling and self-empowerment is one thing that the organization sought to accomplish (Bernstein 1997). As one interviewee said, "NOSSA has made me

feel a little better about myself, knowing that there's [sic] other people concerned about the issue...I mean, just knowing that there's a, a group of people, smart people, you know, that I can talk to and communicate with" (Donna; *NOSSA Interview #3*) and the organization provides this by "letting people know that, um, their voice is being heard, and that there are people out there, and an organization out there, that cares about and understands that what they feel is real" (Donna; *NOSSA Interview #3*).

NOSSA sought not only to create self-acceptance of short statured people, but it also sought to validate the belief of those who felt they had been the victim of heightism and height discrimination, and felt like they had nowhere to turn. One interviewee said: "NOSSA was really a clearinghouse – one-stop-shopping – when there wasn't any other place to discuss, kind of formalize, um, formulate our ideas, and, um, try to serve as a place...where I can talk and kind of everyone's speaking the same language" (Edna; *NOSSA Interview #2*).

Unlike the other two organizations in this study, NOSSA representatives spoke at some length about gender issues as they related to height. And they found these issues directly contributed to the organization's goals: "We provide, um, one ongoing issue for short statured men is finding love. Finding a date...So we have assistance with that. We have singles groups online" (Mike; *NOSSA Interview #1*). This person further described that the dating issue was one of the main concerns of male members of the group. One member even suggested that NOSSA is: "Kind of like a JDate for short people" (Edna; *NOSSA Interview #2*).

Changing Societal Views: Combatting Heightism and Height Discrimination

At the most basic level, NOSSA's message about short stature is that: "Society considers it an undesirable trait. We don't" (Mike; *NOSSA Interview #1*). Members felt that the general public was really unaware of the plight of the short person and the extent of prejudice towards people of short stature. Because heightism tends to be trivialized, or because there is nothing really written about it, people do not know about it: "So they trivialize it, oh, short people can't take a joke, or you know, you've got to pound it over their head" (Edna, *NOSSA Interview #2*). Therefore one of NOSSA's goals was:

To make people more aware of the fact that people are discriminated against based on size. And, because I don't think people think that it's a real issue. But it is a real issue. And there's [*sic*] pay differences based on it, and discrimination in hiring, and um, different issues that revolve around being vertically challenged. People look at you like you can't do a particular job because you're small. And it has nothing to do with you being small, it has nothing to do with your capabilities... (Donna; *NOSSA Interview #3*)

As Donna notes, NOSSA wanted the general public to understand that there are no inherent differences between short and tall people, and that these differences are socially constructed:

I think the primary issue is just, issues of respect. And giving people who are not tall the respect that they deserve. You know, they're human beings just like everybody else...But when I was younger, people just treated me like I had no idea, like I was a child...So it's assumed that, you know, we don't know anything, and we can't do anything, and we need to be directed constantly on what to do. Things like that. And that's not true. We're adults like everybody else. Just not as tall. (Donna; *NOSSA Interview #3*)

The experiences, like the infantilization mentioned in the previous quote, have real consequences for those of short stature. One respondent went so far as to compare the prejudice against short stature to the prejudice against the fat: "I think that there's just, I mean, I think this is an area where, um, where we're just really lagging in understanding

the true prejudice that surrounds, you know, both, both body size in terms of height and weight” (Edna; *NOSSA Interview #2*).^{66,67,68}

Respondents mentioned that two cities, San Francisco, California, and Santa Cruz, California, and one state, Michigan, have anti-discrimination laws that specifically include height. These statutes, however, have rarely been used in practice.

One dream of the organization was to have a presence in lobbying the government: “And there have been a couple of times that they’ve actually gotten a member of congress to try to, um, promote, you know, bills and things like that, for discrimination against vertically challenged people” (Donna; *NOSSA Interview #3*). However, those efforts were ultimately unsuccessful. The same respondent suggested that if the organization could grow in size, maybe it would have more appeal at the governmental level: “[A]nd maybe even start a larger network of people to the point where...we go to Washington, and try to make some changes. I know we’ve had people in the organization go to Washington, but I don’t think that Washington, D.C. looks at anything that we bring to the table...as a serious issue...I think what we need is to grow in size...And then we could get them to listen” (Donna; *NOSSA Interview #3*).

NOSSA’s Ideology: Equal Rights

Rather than focus on height as a disability rights issue, NOSSA looked at it more from the perspective of equal rights:

Um, well we include, by the way, um, people who have, we include, um, people with Achondroplasia, people like that...Um, we feel that, we don’t consider being short a disability...Um, but there are people who are short statured who do have a disability. So, you know, we’re certainly their advocates, and we’ll certainly supporting [*sic*] them. If they’re short statured, we’re there to support them. But

⁶⁶ This comparison will be discussed later in this chapter.

⁶⁷ For more information on fat rights, see Kirkland (2008a).

⁶⁸ In Kirkland’s (2008b) piece, her fat activist respondents often referred to height

no, I wouldn't consider us to be disability advocates per se. *We're short statured people advocates.* (Mike; *NOSSA Interview #1*; emphasis added)

While NOSSA advocated assimilation and can be considered assimilationist, they did not desire assimilation via the utilization of enhancement technologies – changing short bodies to fit into average height society, which I have elsewhere termed “normalization” (Rott 2010). Rather, they wanted to be treated the same as those who are not of short stature. Therefore, NOSSA viewed growth hormone and limb lengthening as practices that discriminate against short people. Further, they felt that it sends the message that short people are undesirable, and that battling against such technologies is difficult in a society that is so bent on changing things that are deemed “fixable”. Mike said: “[W]e're opposed to cosmetic growth hormone use, which is, um, giving a child who is perfectly healthy...just simply short...to give them, um, growth hormone, is kind of like, uh, sort of like having a nose job” (Mike; *NOSSA Interview #1*).

They also felt that these technologies seek to make changes at the individual level, rather than the societal level, which only reinforces the dominant view that being short statured is a negative trait. One participant said, “That this is an area of discrimination, where what we need is education for the purveyors of that discrimination, not this genetic engineering of the victims of discrimination” (Edna; *NOSSA Interview #2*).

Opposition to Growth Hormone and Limb Lengthening

Given the equal rights stance that the group takes, it should come as no surprise that they clearly oppose the use of human growth hormone and extended limb lengthening. The organization was clear that they were not in the business of parent-bashing, but felt that parents should be aware that treating their children's short stature

with medication or surgery is not the answer and that it sends the wrong message to the child and can have deleterious physical and emotional “side effects”:

Mike: We don't come down on parents, we understand that these parents love their children, and they're just trying to do, you know, what they feel is best for their children. We don't attack them in any way: “Oh, you're bad parents”...But we just want them to understand that there's other ways to deal with it. And we feel that, you know, genetic engineering...is not the answer. (*NOSSA Interview #1*)

Edna: And so NOSSA, as an organization, is categorically against growth hormone...And so we stood as an organization that is, you know, one of its main purposes is to alert people to, you know, the potentially dangerous physical side-effects, but also the emotional, psychological side-effects, of being injected with growth hormone. (*NOSSA Interview #2*)

While NOSSA members showed some understanding about why parents may seek out growth hormone treatment for their children, NOSSA leaders had little sympathy for the pharmaceutical companies, “which have capitalized [on the] prejudice against short people”:

To take a normal curve and label 5% of that normal curve as abnormal and in need of treatment, is purely a social prejudice. And it's a way to expand pharmaceutical profits because now they have a surplus of the synthetic hormone...To me it's just so outrageous. You've got so many children in this country who have no health insurance at all. Nothing. And yet we have insurance companies...wealthy families insistent on getting some diagnosis where it's going to help them cover 20 or 40 thousand dollars a year. For something like this. So I just think, on so many levels, it's outrageous... (*Edna; NOSSA Interview #2*)

In addition to their concerns about the cosmetic nature of growth hormone use in short normal children, and the limited height increase that is typically the result, the unknown side-effects were also key to the organization's concern in relation to growth hormone.

As one participant said: “But the drugs themselves are not seen as safe, and they're dangerous, and really, why would we even need such a drug if there wasn't discrimination against being short in height” (*Donna; NOSSA Interview #3*)?

Another participant even went so far as to call the National Institutes of Health (NIH) trials testing growth hormone on healthy children that took place in the 1980s and 1990s (Tauer 1994) and the 2003 Food and Drug Administration (FDA) approval of growth hormone for short normal children as, “government sanctioned prejudice and discrimination” (Edna; *NOSSA Interview #2*). The use of words like “prejudice” and “discrimination” peppered the interviews I conducted with three members of NOSSA; and it is important to note that the tenor of these comments is clearly distinct from the other two organizations already discussed in this dissertation.

The organizational response to limb lengthening was much the same as it was to growth hormone:

The average adult male height in this country is 5’9” [it’s actually now 5’10”]. So that’s telling you about how insane the social prejudice can be. That you’re willing to let, that even an average height male isn’t tall enough, and we would consider doing this leg lengthening, it’s excruciating. And it’s dangerous. And again, if there’s a medical reason for it, it’s a great thing to have as an option. But as a social prejudice, to be, I mean, as I’m sure you know what’s involved in the surgery, and it’s horrendous. You can be out of commission for two or three years, and never really regain full use of your legs. I mean, it’s terrible. It’s, social prejudice that’s, it’s, it’s so out of the realm of my understanding... You know, to me it’s worse than any kind of mutilation. (Edna; *NOSSA Interview #2*)

There was also a suggestion that supporting these technologies now, or allowing them to proliferate without calling into question their appropriateness, will only create a further need for new technologies to mitigate the “problem” of short stature in the future:

There’ll be a discussion about it. And I don’t even think that they’ll, um, say it’s a bad idea. I think they’ll just look for another way of, um, another kind of technology to try to increase height. And that’s what’s, you know, it’s like looking at something and never getting to the root of the problem. The root of the problem is a bias that’s favoring the tall over the short... And until we, until we look at that, you know, taking African Americans and making them white, taking short people and making them tall, taking fat people and giving them gastric bypass. It’s, it’s a ridiculous way to look at... the prejudices our culture has created. (Edna; *NOSSA Interview #2*)

As the above comments suggest, it is not the technologies in and of themselves that NOSSA opposes. Rather, it is the use of these technologies to “normalize”, that NOSSA activists find unacceptable. NOSSA believes that people should be viewed equally as they are, without having to change their appearance to be considered equal.

This portrait of NOSSA was based on the interviews with its officers and members conducted in the Summer of 2011. In less than two years, NOSSA had all but vanished from cyberspace. An announcement that it no longer existed and some farewell messages from officers were the only evidence it had ever existed. NOSSA’s strange demise demands an explanation, which I provide in the remainder of this chapter.

Why NOSSA Failed: A Sociological Autopsy

Structural Factors: Informal Organization

The activists that were involved with NOSSA were most often actively recruited by the organization. Although the organization had a Board of Directors – consisting of a President, Vice President, Treasurer, and Secretary – the members I interviewed seemed to view themselves on the same level with those considered to have been part of the leadership of the organization at one time or another. One reason for this may be that they were actively recruited by NOSSA. One interviewee said: “And because of that book [a book she wrote about her short stature], they just kind of found me. And asked me if I was interested in the organization, and I said ‘Absolutely.’ So that’s kind of how I did that” (Edna; *NOSSA Interview #2*).

Suzanne Staggenborg’s (1988) distinction between the professionalization and formalization of social movement organizations is instructive in the case of NOSSA. The leadership of the organization consisted entirely of volunteers. Aside from those who

were Board members, there seemed to be only a small cadre of active members, and the resulting rank-and-file seemed rather uninvolved. This lack of division of labor is one characteristic of an informal organization (Staggenborg 1988). Moreover, the fact that the organization was online-only may have contributed to the lack of differentiation between leaders and rank-and-file members of the organization (Earl and Schussman 2003).

As Staggenborg (1988) suggests, SMOs can take on characteristics of both formal and informal organizations, and while we see this slightly with NOSSA, the organization follows more of an informal scheme. While there was a Board of officers, NOSSA's board seemed to exist largely on paper. The Board appeared to serve a symbolic and ceremonial function, necessary for NOSSA to appear legitimate, rather than for practical purposes (DiMaggio and Powell 1983). Moreover, although the organization charged dues, its membership requirements and what it meant to actually be a member of the organization, were unclear, which is consistent with informal organizations, that tend to "[H]ave few established procedures, loose membership requirements, and minimal division of labor" (Staggenborg 1988: 590).

Further, it seems to me that NOSSA served as a catch-all group for those who did not belong to either LPA or MAGIC, either by rule or by choice. In LPA and MAGIC, those involved are clearly defined as dwarfs, in the case of LPA, and sick, in the case of MAGIC. Those who do not fit into those categories are left on the margins. They can either slink quietly away, or they can join an organization consisting of adult activists.⁶⁹ Thus, NOSSA's membership requirements were more fluid than those of the other two groups, which also speaks to the informal nature of the organization (Staggenborg 1988).

⁶⁹ One of my respondents, who was 4'8" (on the taller end of the LPA spectrum), suggested that because her body was proportional, she did not fit in to LPA.

At the most basic level, “[F]ormalized SMOs are able to maintain themselves – and the movement – over a longer period of time than are informal SMOs” (Staggenborg 1988: 597).

Membership, Recruitment, and Resources

As social movement researchers have often noted, what distinguishes a social movement from more transient forms of collective behavior is the presence of an enduring organization. The existence and endurance of organizations depend, in turn, on resources, and NOSSA lacked two of the most rudimentary, interrelated resources: Money and an active membership. To engage in lobbying and the kind of political activities NOSSA’s leaders one day hoped to do, would have required more funding than could be raised through the annual dues of a small number of members. Moreover, NOSSA’s informal organizational structure contributed to its lack of resources since formal organizations are more able to obtain funding (Van der Veen and Klandermans 1989: 179).

NOSSA was an organization that consisted of a small group of leaders, whose role was largely ceremonial, a few members who were actively involved in the organization and the majority of members, whose participation was limited to paying dues and online discussions. As social movement researchers have noted, there are three types of voluntary participation: 1) membership, 2) active membership, and 3) collective action. It therefore seems clear that “membership – without engagement in organizational activities” – is not enough to sustain a social movement organization when there is only a small cadre of active members and the majority are merely members in name only (Van der Veen and Klandermans 1989: 179). Further, in order to put time and effort into an

organization and for membership in an organization to flourish, members must view the perceived benefits of being part of an organization as greater than the risks of participation or donating their name to a cause; members may have felt that there were no real incentives or benefits for those who participated in the organization as compared with those who did not (Klandermans 1984; Olson 1977; Van der Veen and Klandermans 1989).

NOSSA's inability to build a large base of active members can, in part, be attributed to its recruitment strategies. Reliance on the leadership to recruit members on an individual basis – as those I interviewed suggested, rather than having people come to them, may be another reason why the organization was doomed to fail (Schussman and Soule 2005; Snow, Zurcher, and Eklund-Olson 1980). When you cannot get your constituency to come to you, and there are no obvious players out in the world to approach, what is an organization to do? Given the small number of members and a still smaller subset that was very active, there may not have been the strength in numbers needed to sustain the organization. As Van der Veen and Klandermans (1989) have observed:

In SMOs, however, where the recruitment of new members often is a struggle to start with, a decline in membership makes for serious difficulties. Once a certain critical point is reached, the organization simply ceases to exist, on account of, first, the lack of material and immaterial means (these organizations depend heavily on material and immaterial contributions by members); [and] second, because of the dwindling potential manpower that can be called upon for collective action...(180).

Collective Identity

NOSSA's ideology shares some common features with other social movements that, unlike NOSSA, have endured or even thrived. In its insistence on the right of full

participation and integration into society, its goal of ending discrimination, and its use of equal rights frames. NOSSA is similar to one of the most enduring and successful assimilationist social movements: The disability rights movement. Beginning in the 1970s, disability rights activists have urged that once architectural barriers were removed and reasonable accommodations made, people with disabilities were capable of full economic and political participation. However, here the similarity ends: NOSSA's leaders repudiate the view of themselves as disabled. Thus in contrast to the disability rights movement, NOSSA's stance would not include a demand for reasonable accommodations or removal of architectural barriers. NOSSA's leaders emphasized that short statured adults were fully capable of equal participation and, hence, no accommodations were necessary.

NOSSA's stance of not considering themselves disability activists or members of a disability group is similar to that of the Deaf. The Deaf have rejected the label of a disability group and some suggest that they should be viewed as an ethnic group instead (Lane 2005).⁷⁰ Further, Lane (2005) outlines four reasons as to why the Deaf should not be considered a disability group: 1) they do not view themselves through that lens; 2) it creates risks for the deaf child; 3) it poses a survival risk to Deaf culture; and 4) it allows for the proliferation technologies, such as cochlear implants, that can be used to eugenically eliminate them (297-305). Because they view themselves as a culture, rather than as having a disability to be "cured," the Deaf have opposed the use of cochlear implants, which they view as a eugenic program that would ultimately result in the destruction of their culture. Despite their officially neutral stance on limb lengthening, the

⁷⁰ Lane (2005) puts forth 11 properties of ethnic groups: Collective name, feeling of community, norms for behavior, values, knowledge, kinship, customs, social structure, language, art forms, and history.

LPA, like the Deaf, are deeply troubled by the potential of genetic technologies to eliminate short people. In their refusal to view themselves as disabled and their opposition to technologies that can be used for eugenic aims, NOSSA's activists are ideologically similar to LPA and the Deaf.

In contrast to LPA and the Deaf, however, what concerns NOSSA most is full integration into mainstream society. One reason why NOSSA activists refused to identify themselves as “disabled” is because the label implies, in their view, that they are less than fully capable of equal participation. What most concerns LPA and the Deaf is their continued survival as a distinct culture or ethnic group: They insist that their difference is not a disability to be cured or eliminated, but a culture to be celebrated and perpetuated. Given this identity politics, it is not surprising that the Deaf and LPA advocate marrying and having Deaf and LP children or that some activists have even advocated using genetic technologies such as pre-implantation genetic diagnosis (PGD) to ensure they have Deaf or LP offspring – an idea that remains controversial. Members of NOSSA do not view short statured adults as a distinct culture to be preserved and celebrated, and it is inconceivable that they would even consider endogamy or PGD. Their goal is not the survival of a difference, but rather equality and integration.

The social movement that is most similar to NOSSA is the National Association to Advance Fat Acceptance (NAAFA). Like NOSSA, NAAFA used an “equal rights” framework and demanded assimilation or participation in society-at-large as equals. According to its mission statement, NAAFA is a “civil rights organization dedicated to protecting the rights and improving the quality of life of fat people” that “works to eliminate discrimination based on body size” in areas of life that include employment,

education, health care, and adoption and child custody (The National Association to Advance Fat Acceptance 2013a). NAAFA advocates legislation that adds “height and weight” discrimination to categories protected under equal employment statutes. There are other similarities between NAAFA and NOSSA: Members of both organizations do not view their condition (short stature, fat) as a disability and oppose the use of enhancement technologies to “correct” their condition: “NAAFA believes that the psychosocial suffering that fat people face is more appropriately relieved by social and political reform than surgery” (The National Association to Advance Fat Acceptance 2013d).

However, in contrast to NOSSA, NAAFA is not only concerned with attaining equality and social acceptance, but is equally dedicated to promoting the *self acceptance* of its members. Its convention includes fashion shows, dances, and other social activities, as well as lectures. Like LPA, it seeks to create, foster and celebrate Fat identity, most recently under the slogan “We come in all sizes” (The National Association to Advance Fat Acceptance 2013a). NAAFA is about identity politics as well as advocacy.

As I have suggested, NOSSA’s ideology was similar in many respects to the Deaf, LPA, and NAAFA. What distinguished these groups from NOSSA was their strong sense of collective identity – an identity as a separate culture or one created through identity politics. In NOSSA, by contrast, a collective identity was noticeably absent.

What led the Deaf, LPA, and NAAFA to create and sustain a positive collective identity while NOSSA was either unwilling or unable to do so? When we compare the Deaf, LPA, and NAAFA to NOSSA, we find two important differences. First is the degree of segregation, stigma, and social exclusion that the Deaf, LPA, and the Fat

experience – experiences that have forced them, to a greater or lesser extent, to be separate from society-at-large. It is easy to understand why many Deaf would prefer communicating with ease in American Sign Language (ASL) to being forced into marginality in the hearing world. For LP's and for the Fat, organizations of people with similar conditions provide a refuge from the harsh realities of prejudice, discrimination, and stigmatization they encounter in the outside world. Second, all of these other groups have some form of interaction apart from the Internet. The importance of face-to-face communication with like others in creating a positive collective identity, cannot be overstated. In the case of NAAFA and LPA, dances, and fashion and talent shows that take place at the convention are all designed to foster and celebrate a sense of belonging and a positive collective identity (The National Association to Advance Fat Acceptance 2013b). Without this separation and the opportunities for in-person contact with like others, a sense of “we-ness” and a collective identity cannot emerge. In the case of NAAFA and LPA, a strong collective identity and sense of belonging have powerful consequences for members' self-esteem. They serve to sustain members' commitment to the organization and help us understand why these organizations have endured.

Another piece of collective identity that was missing for members involves the fact that the members of NOSSA may not be as visible, and therefore, height may not have been as salient of a factor in the lives of NOSSA members as it is, for say, those involved in LPA. For LPA members, their status as Little People is clear and undeniable, not only to themselves, but to the outside world, as well. And this lack of saliency most likely contributed to the organization's lack of survival.

Another reason for the failure of NOSSA's members to develop a strong collective identity has to do with the nature, extent, and visibility of the physical difference itself (Anspach 1979). Because their physical difference was not as pronounced, height may not have been as salient a factor in the lives of NOSSA members as it is, for example, for members of LPA. For LPA members, their status as Little People is clear and undeniable, not only to themselves, but to the outside world, as well. For most LPA members, "passing" was simply not an option. But for members of NOSSA, who may be shorter than average, but not necessarily profoundly short, their height may not be something that they found themselves having to deal with on a daily basis. This lack of saliency may have limited their awareness of discrimination or made it less likely that they would develop a sense of sharing a set of common interests with other short-statured people. Thus the lack of saliency most likely contributed to the organization's lack of survival.

Online Community and Anonymity

NOSSA was basically an online-only entity: Nearly all of the organization's activities taking place online (Earl, et al. 2010). The organization was run out of the President's home.⁷¹ Unlike other organizations, there was no conference for me to attend, and no magazine or weekly newsletter to read. While the Internet is open to social movement organizations with fewer resources, because start-up costs are low, this lack of resources may carry over and ultimately have a negative impact on the organization as a whole (Earl, et al. 2010).

While the organization tried, with limited success, to increase the number of activities that took place offline, there was another reason for the reliance on the Internet:

⁷¹ With a membership that is ten percent of that of LPA, this is not a surprise.

“Because of the nature of the issues we discuss[ed], which is heightism and height discrimination, there’s a lot of stigma associated with it. So a lot of people, uh, appreciate the anonymity of the Internet. So, yes, our full communication is done online” (Mike; *NOSSA Interview #1*). While this anonymity offered a veil of protection to participants, it begs the question as to how a group of strangers can create a cohesive collective identity when they do not actually know each other beyond an anonymous, online persona.

However, there are examples of other stigmatized groups that have found success online, despite their anonymity.⁷² This is seen in the case of contested illnesses and stigmatized conditions such as chronic fatigue syndrome and multiple chemical sensitivity (Dumit 2006), fibromyalgia (Barker 2008), and pro-anorexia (pro-ana) websites (Boero and Pascoe 2012; Giles 2006). These groups have been able to create positive illness identities and have also provided each other with strategies for navigating the healthcare system, creating a shared collective identity, and validating members’ concerns relating to their illness.

Another example is the Neurodiversity movement, in which the Internet has allowed those with autism to communicate with each other, when they may find face-to-face interaction difficult. In fact, the anonymity offered by the Internet has allowed such groups to proliferate, where previously there had been little in-person support available to such groups. Although in these cases, it would seem that members of these sites share a collective identity based on illness experience, this does not seem to have been the case with NOSSA.

For the rank-and-file of NOSSA, the main mode of participation was through online forums and message boards. Unfortunately, the forums were unable to provide a

⁷² By using pseudonyms, usernames, or first names only

place where members, even with the safety of anonymity, could get validation and support for their sense of being discriminated against because of their short stature, as was evidenced in a particular incident that occurred on the forum. When a member complained about their experience with discrimination, their concerns were invalidated and trivialized, and they were told in so many words to “stop whining”. In this instance, the leadership did not intervene and did nothing to attempt to channel the discussion in a more positive and supportive direction.

While the Internet could have served to help foster a sense of collective identity, shared grievances, and potentially even created a political consciousness within the organization’s rank-and-file, in some cases, the Internet actually proved to be a divisive space and de-politicized the rank-and-file of NOSSA. These types of exchanges, like the one just mentioned, hardly created incentives for others to share their experiences or to participate in an online community or for one to form, let alone cause widespread mobilization on the part of the NOSSA membership.

Collective Inaction

In addition to providing a vehicle for consciousness raising, NOSSA also had broader political goals that included engaging in advocacy and political action to combat prejudice and discrimination based on short stature in society-at-large. They sought to do this through lobbying, speaking to the media, legislative action, and legal action. Although this was one of the organization’s main goals, it was never realized. NOSSA never engaged in political action of any kind.

A comparison with NAAFA would be useful in this regard. NAAFA, which has a similar ideology to NOSSA, has actively spoken out to the media against activities that

represent prejudice and discrimination since the organization began in 1969. Further, NAAFA has participated in several successful anti-discrimination lawsuits against employers who have wrongfully terminated Fat employees and continues to offer support and to suggest expert witnesses. It also organizes boycotts, protests, and letter-writing campaigns, and issues press releases to comment on policies that affect Fat people.⁷³

There was at least one missed opportunity for NOSSA to engage in political action. Patrick Burns III, a police sergeant in Bayonne, New Jersey, filed a lawsuit against the city alleging that he was harassed at work as a result of his short stature. In one instance, Burns alleged that his fellow officers superimposed his face onto a picture of Napoleon Bonaparte⁷⁴ and taped it to his locker. In return, the city countersued and fired Burns, and then reinstated him after a six-month suspension.⁷⁵ While this case was mentioned on the NOSSA blog, nothing else was done by NOSSA. NOSSA could have utilized the Internet to mobilize its members, to encourage them to rally or protest in demonstrations, or to solicit funds to support the lawsuit. A firm backing from the organization would not only have brought publicity to the organization, but it also would have given legitimacy to Burns' claims of discrimination.

The effects of political action are synergistic: Political action can strengthen an organization, and conversely, while such activities may pose minor risks, legal action can galvanize members, foster a sense of collective moral outrage, and in fact, can provide

⁷³ On the other hand, however, while NAAFA has been widely successful in taking legal action, they have had minimal cultural impact.

⁷⁴ Napoleon Bonaparte was a French military leader known for his characteristic short stature. The Napoleon Complex – a term referring to the aggressive nature of short men thought to be compensating for their lack of height – is also named after the famed French leader.

⁷⁵ It is unclear what the ultimate outcome of the case was or whether it was ever heard in court. More information about this can be found in Leir (2007) and MassCops (2007).

the organization with a concrete rallying point.⁷⁶ These activities have the potential of raising the political consciousness of members and can serve to strengthen the organization, as a whole. It can give members the sense that there is an organization that stands behind them in their struggles. While those actively involved in the organization seemed to feel (as quoted earlier) that the organization did this, it is clear from the description of the forum, that most members of the rank-and-file probably did not feel this way. Being more politically active could also have provided the opportunity for NOSSA to seek alliances with other, similar groups. NAAFA and NOSSA could have coalesced as two organizations that focus on issues of body size. Therefore, failing to engage in legal action was a missed opportunity, both within and outside of the organization.

Given the uniqueness of each employment situation and the risks involved in litigation, combatting height discrimination in the workplace may have been too much for individuals to attempt: These are problems that are more effectively addressed at the organizational level (Snow and Soule 2010). And while NOSSA sought to take on some of the major issues, such as heightism and employment discrimination, that LPA avoided, political action eluded them. While the equal rights frame should have been salient for short statured people, it appears that many of NOSSA's members may not view their height as an issue worthy of their personal devotion to an organization (Snow and

⁷⁶ The few laws that were mentioned earlier that specifically include height discrimination, were put in place before NOSSA was created, and despite knowledge of them within the organization, do not seem to have been utilized at a greater rate because of the existence of the organization, itself. While it may seem like the existence of such laws would give credence to those who have experienced discrimination based on height and/or seek out NOSSA, it is not that simple. Those who file cases of employment discrimination will likely lose whatever job they are fighting for, and may be seen as rabble-rousers or worse, and may find it difficult to obtain employment opportunities in the future. NAAFA confirms that laws, such as the one in Michigan that includes weight discrimination along with height discrimination, have rarely been utilized (The National Association to Advance Fat Acceptance 2013c).

Benford 1992a; Snow, et al. 1986) and they failed to create a consistent and coherent group consciousness (Taylor and Whittier 1992).

In order for groups to politicize or create a political consciousness, the group has to do three things (Levitsky 2008). First, the group must identify grievances, known as “naming” (Felsteiner, Abel, and Sarat 1980). Second, the group has to have an ideology that locates the problem outside of the individual, known as “blaming” (Felsteiner, Abel, and Sarat 1980). And third, the group has to be able to turn grievances into collective action, known as claiming” (Felsteiner, Abel, and Sarat 1980). In the case of NOSSA, we can say that politicization was partial. First, while leaders had a well-formed ideology (“blaming”) and grievances (“naming”), they were unable to recruit the rank-and-file to the organization. Second, while NOSSA was able to form grievances (“naming”), they were not able to translate those goals into political action (“claiming”). In this way, politicization remained partial – a fact that contributed to NOSSA’s demise.

Conclusion

As of the end of December 2012, all indications were that NOSSA was poised to begin a new year. But it was announced on January 15, 2013 that “NOSSA Set To Close It’s Doors.” Part of the statement read:

It is with a very sad heart that we regretfully report that NOSSA – National Organization Of Short Statured Adults, Inc. will be closing it’s [*sic*] doors. Over the next year the organization will be closing up shop and will no longer continue to operate. *The main reason for this is due to a lack of support from the short statured community.* Without support no organization can continue and unfortunately, NOSSA fell victim to this very basic truth. (National Organization of Short Statured Adults, Inc. 2013d; emphasis added)

Several blog posts followed that announcement, including “NOSSA Secretary [*sic*] Thoughts” (posted on January 19, 2013), which read in part:

I have to say that more so than NOSSA coming to a close, the thing that pains me is the reason behind it needing to do so and that is the indifference toward heightism and the fact that most people think it is a joke...I would also like to add that while I was still holding my notions about how wrong heightism was inside, NOSSA was out there in the world in the face of overwhelming odds...*So while the family name may be fading, that doesn't mean we can't continue the great family tradition we have cultivated here. It's sad to see this legacy coming to a close before a decade even elapsed, but all of you who got this momentum started, just know that your efforts weren't in vain* (National Organization of Short Statured Adults, Inc. 2013c; emphasis added).

A “Message from NOSSA President” (National Organization of Short Statured Adults 2013a; posted on January 24, 2013) echoed similar sentiments, suggesting that there had not been enough participation from the short statured community. In analyzing NOSSA’s failure in this way, the leaders seem to be blaming everyone but themselves.⁷⁷ However, it is clear that NOSSA needed its leaders to mobilize the rank-and-file, to create more face-to-face interaction with members, and support causes that could be a rallying point for members. However, this did not happen, and it begs the question: If you cannot convince your own constituency of your worth, what hope does an organization have, not only of convincing others, but merely of staying afloat in a world that is full of causes and pet projects? Rather than raising the consciousness of members, the leadership left it to the unmediated design of the online forum, sometimes resulting in de-politicization of the organization.

By trying to change societal views and improve the treatment of short people by average height society, was an attempt to ameliorate grievances and level the playing field, but for this group, they may have felt that they had nothing left to lose. It is much

⁷⁷ As of May 17, 2013, NOSSA officially closed its doors with the following blog post, titled, “NOSSA Closed It’s [*sic*] Doors”: “NOSSA - National Organization Of Short Statured Adults, Inc. is no longer in operation. We encourage past supporters of the group to visit websites such as www.shortsupport.org for more information and assistance with height discrimination and related issues. We wish everyone who has supported us through the years only the best. Thank you” (National Organization of Short Statured Adults 2013b)! And the organization’s website is no longer available.

easier for a group to try and protect rights from being lost, rather than trying to advocate for things that the group does not yet have, such as equal rights (Snow and Soule 2010). One respondent said, “You know, we have some people who are cynical, who are saying, ‘This is just the way life is, it’s never going to change.’ I like to think, if you ask me personally, I like to remain optimistic. And I do think things will get better...And I think the organization is definitely helping to facilitate that” (Mike; *NOSSA Interview #1*). Despite this respondent’s enthusiasm, it is clear that not everyone in the organization shared this sense of optimism and hope, which is necessary for mobilization (Snow and Soule 2010).

And despite their equal rights perspective, or maybe in spite of it, NOSSA was unable, it seems, not only to convince the general public about the issue of heightism, but the short statured community, as well. This suggests that even in our technology-driven and technology-dependent society, there is something to be said for in-person, face-to-face interaction, even if it only happens once a year (as in the other two organizations under study here). While the Internet can connect people from around the country and world who would not have any other way of interacting, it remains unclear whether enduring relationships can be created and sustained online (Cerulo and Ruane 1998).

Our “sociological autopsy” suggests that a number of factors contributed to NOSSA’s demise. None of them in itself was responsible, but taken together, these factors weakened the organization and led to its demise. A lack of resources (money, active membership) and a very individualized recruitment strategy resulted in an informal organizational structure and a weak leadership that failed to galvanize members or inspire political action. Relying on the individualized motivation of members to start their own

chapters as a means of creating more in-person interaction was an event which never coalesced. NOSSA's remained a virtual, online organization without an annual convention that could have served as a catalyst for the emergence of a strong collective identity. NOSSA's virtual community was a community in name only that failed to validate members' concerns and revealed a membership that was not invested in the goal of assimilation and equal rights for people of short stature. Without a strong collective identity or a case to serve as a collective rallying point, NOSSA provided its members with few benefits attached to active participation. Together, these factors made for a lethal combination that caused the organization to cease operation. I conclude this dissertation by comparing and contrasting the three organizations that have been discussed in this and the previous two chapters, and suggest areas for future research.

Chapter 5:

Conclusion

Bodily differences and variations are found in all societies, but only some of these differences are singled out for prejudice and discrimination. In American society, short stature is one of those attributes in which a statistical fact – height difference – has been societally defined as discrediting and stigmatizing (see Goffman 1963). This dissertation has described and analyzed how three groups have collectively grappled with the stigma that is attached to short stature.

In order to fully understand how social movements have organized around short stature, all three organizations must be examined together, as there are both distinct similarities and differences between them. One cannot fully understand one organization without understanding it in the context of the others.⁷⁸ In this chapter, I first provide a comparison of LPA, MAGIC, and NOSSA (see Appendix B). Next, I then discuss the turf wars that exist between the organizations and how this impacts movement success. I then will attempt to explain the lack of activism around heightism and height discrimination. Finally, I conclude by describing what the reader should take away from this story, and areas for future research.

⁷⁸ One caveat, however, is that none of these organizational ideologies are perfect. To privilege one over the other would be to take credence from those who are involved in the group, and would fall victim to one of the pitfalls of identity politics.

Comparing the Organizations

Framing: Three Views of Enhancement (and Reproductive) Technologies, and Fear of Eugenics

At the most basic level, the three organizations under study here have differing frames for viewing the issue of short stature, and also differing views on using both enhancement and reproductive technologies.⁷⁹ MAGIC views short stature as an undesirable abnormality or even a social affliction. Its goal is to normalize or to make short children fit into “normal” or dominant society. Sharply contrasting with MAGIC is LPA, which seeks to celebrate the unique culture of people with dwarfism, and NOSSA sought to have short people viewed as being equal to tall people in American society. In terms of the view of using enhancement technologies, MAGIC was pro-technology, LPA was equivocal on using technology, and NOSSA was anti-technology.

For members of MAGIC, science and technology become “weapons” in a battle to “cure” short children of their “affliction” by making them taller. MAGIC views enhancement technologies or growth hormone as the key to gaining the benefits that height brings for those who are not short statured. Acutely aware of the ambivalence with which our society views plastic surgery and other forms of enhancement, MAGIC’s leaders seek to legitimate the use of enhancement technologies by constructing a narrative that identifies height with health. While the leaders of MAGIC claim that they are not for giving healthy children a competitive advantage, my interviews with parents of children with Idiopathic Short Stature (ISS) and Growth Hormone Deficiency (GHD), show that this is exactly what they want for their children. Parents are less concerned

⁷⁹ Although it was not the explicit goal of this dissertation to look at reproductive technologies, this was something that was borne out of the interviews with both organization leaders and members.

about all children of short stature, but rather, they are worried about their own child being the shortest in the class, and concerned with how their child will be defined and treated by others. While MAGIC is pro-enhancement technologies, they do not, however, advocate the use of “eugenic technologies” to accomplish increased height. They take already short children and make them taller, rather than making sure no short children are ever born. This makes sense given that if there were no short statured people, there would consequently be no tall people, and there would be no reason to use enhancement technologies to gain the benefits of height.

While LPA’s official position treats the use of enhancement technologies as the personal choice of its members, several members viewed such technologies as posing potential problems for the dwarf identity. For instance, some asked, what does it mean to be a tall dwarf? (See Chapter 2 for a further discussion of this issue). However, because most Little People would still be considered short, even if they utilized growth hormone or limb lengthening, such technologies are seen as less of an issue in the organization than the use of reproductive technologies, such as pre-implantation genetic diagnosis (PGD), which is seen as a clear threat to the unique culture of the LP community. LPA adamantly opposes the use of such technologies that would allow for the selective abortion of dwarf fetuses, which could ultimately have the effect of wiping out the LP population altogether. In fact, LPA comes close to advocating what might be called “defensive eugenics”, or selectively aborting average height fetuses, and having dwarfs marry other dwarfs as a way of perpetuating their unique culture.

NOSSA viewed enhancement technologies as a misguided attempt at an individual solution to what is in fact a societal problem; in other words, as a wrong-

minded way of gaining social acceptance and achieving equal rights for short-statured people. And similarly to LPA, NOSSA was also concerned about the use of reproductive technologies used to screen out short statured embryos. While NOSSA voiced clear and pointed opposition to the use of enhancement technologies and voiced concern over the slippery slope that could be caused by reproductive technologies, it appears that their opposition did not resonate with the general public or even with members of their own organization.

To summarize, how groups viewed enhancement and reproductive technologies flowed directly from the way they framed short stature itself. For MAGIC, human growth hormone is a technological tool or even a weapon to be used in “curing” the social affliction of short stature. For LPA members, who view dwarfism as a unique culture to be celebrated and perpetuated, enhancement technologies, which are rarely used, are less threatening than are reproductive technologies, which pose a threat to the very culture that they seek to celebrate. For NOSSA, the problem was society’s discrimination on the basis of height, and enhancement technologies were misguided efforts to achieve an individual solution to a social problem; and reproductive technologies represented social prejudice in its most extreme form.

Collective Identity

Of the three organizations, LPA is really the only organization able to establish a collective identity among its members and leaders. This collective identity or group consciousness (Taylor and Whittier 1992), or the agreement of members of the rank-and-file with the views of the leadership, suggests that members of a group must have like-minded views of the main goals, mission, and purpose of an organization in order for it to

gain legitimacy and staying power. Establishing a collective identity allows a group to present a united front for society-at-large, and prevents splintering and factionalization.

For LPA, the collective identity that was created was positive and focused on celebrating the unique culture of those with dwarfism. This was seen, not only in how both organization leaders and rank-and-file members talked about the organization, but it was also seen in how the organization was run. The nightly dances, and the fashion and talent shows at the annual conference, were a tangible expression of this positive collective identity – rituals in which a positive identity was enacted, displayed, and recreated.

For MAGIC, there was not really collective identity as much as there was a collective goal. This is because the views of the organization’s leaders and rank-and-file members were quite different. While leaders advocated the “height as a proxy for health” ideology, parents were more likely to push forward simply wanting their children to be taller. Parents actually wanted their children to *escape* the identity of being short. Overall, however, the goal to normalize short children was shared by both the leaders and parent members of MAGIC. Leaders felt that normalization was attained by pursuing health, whereas for parents, normalization meant attaining a “normal” appearance in terms of height, with all the privileges they believe it would bring.

In contrast to LPA, NOSSA was unable to establish a collective identity, and this is a key reason for the organization’s ultimate failure. Given the organization’s online-only structure, it may have been difficult for members to feel connected to other anonymous, online personae. Further, there was a lack of collective identity between those most involved in the organization and those who were simply general members.

This is seen in the organization's lack of resonance with the short statured community, which leaders pointed to as the main reason for the organization's demise.

Both LPA and MAGIC based their organizations along diagnostic lines, implicitly in the case of LPA (member created), and explicitly, in the case of MAGIC (leadership created). For NOSSA, simply being short may not have been enough to create resonance with other short-statured people, and therefore, a collective identity. By including all people of short stature, there may have been too much diversity of experience for members to unite. For example, the experiences of a man who is 5'7" may not be that different from a man who is 5'9", as compared to a man who is 5'2" or 5'3". So the lack of empathy that was present in the organization may have been a result of some group members feeling more aggrieved than others.

Similarly, the evident-ness of the height difference as compared to that of average height society inevitably causes some groups to have more saliency amongst their members than others. For example, those in LPA, who are of extreme short stature, are not able to pass in regards to their height. In other words, their height is always a visible and noticeable difference, and is something that they have to deal with constantly – and this difference draws them to an organization that wholeheartedly celebrates that difference. For members of MAGIC, while there may be a visible difference, depending on the condition, the evident-ness of the height difference is often magnified by parents and doctors, who are most often the ones to show a concern for a child's short stature. And given their stance on technology, MAGIC seeks to erase the evident-ness of short stature, allowing short children to pass as average height. For NOSSA, because group members, while short, fall more within the "normal" range than members of LPA, their

difference is less visible and they are more able to pass in average height society, making their height a less salient factor in their lives – and thus making membership in the organization less of a necessity.

Organizational Structure and Involvement

LPA and MAGIC are both examples of formal organizational structures, whereas NOSSA is an example of an informal organizational structure. Formal organizations tend to have “established procedures,” “bureaucratic procedures for decision making,” a clear division of labor, and clearly defined membership criteria; while informal organizations “have few established procedures, loose membership requirements, and minimal division of labor” (Staggenborg 1988: 589-590). Formalized SMOs tend to persist for a longer period of time than informal SMOs are able to (Staggenborg 1988). We see this in the fact that LPA and MAGIC continue to thrive and resonate with their constituencies, while NOSSA was unable to survive as an organization.

LPA and MAGIC both host annual conferences that not only allow members to meet each other, and in the case of LPA, for relationships between members of the opposite sex to flourish, but it is also an occasion in which organizational ideology is promulgated. For LPA, this means that those presenting at the conference share the views of the leadership, and further espouse the core beliefs of the organization. For MAGIC, this means allowing pharmaceutical companies to play a large role in the lives of their constituents, influencing them to use enhancement technologies. NOSSA, on the other hand, did not have an annual conference, or really any institutionalized way for group members to gather in person, suggesting that for LPA and MAGIC, the annual conference is a key part of keeping the organization alive.

Further, aside from the annual conference, LPA had a newsletter/magazine, archives, a staff and board. MAGIC similarly had, along with an annual conference, a weekly newsletter, a staff, and board. NOSSA was nearly entirely online and did not really have any of the institutionalized aspects that LPA and MAGIC do. While LPA and MAGIC both had a staff and boards, all three organizations relied almost exclusively on volunteers. This shows the importance that members place on the organization in their lives and the lives of their families; but it also suggests the importance of having a more built-in staff that manages the organization besides simply having everyone participate on a volunteer basis.

One characteristic shared by both LPA and NOSSA is that they were often referred to as “dating services”. This is seen in the nightly dances that take place at the LPA annual conference. For NOSSA, it is seen in the fact that many of the male members of NOSSA actively sought out the organization in order to get help in the dating realm, as it can be difficult for short men to find partners. For MAGIC, since the children are very young, this is not seen as an explicit goal. However, turning short children into average height children with the use of enhancement technologies means that, ostensibly, those children will have an unlimited pool of mates in terms of height once they are of average stature (and old enough to date).

The make-up of those involved in the organizations is also a point of differentiation. While NOSSA was made up of adult activists, parents play an active role in both LPA and MAGIC. As a result, parents involved in both organizations receive a “courtesy stigma” as a result of their children (Goffman 1963). In LPA, this is seen in the average height parents of LP children. While those of average height who show interest

in the organization are met with skepticism, average height parents of LP children are embraced. In MAGIC, parents are the key constituency of the organization, identifying that there is a “problem” with their children, and seeking out the organization for advice, support, and ultimately, treatment.

The Internet

For all three organizations, the Internet has become a key in how the organization works and attracts members. For LPA and MAGIC, the Internet has allowed them to broaden their membership, and keep in closer contact with their members. For NOSSA, the Internet was the platform that kept the organization alive, for a time, despite a lack of actual activity. As seen in the case of NOSSA as compared to LPA and MAGIC, however, while the Internet is a critical part of social movement organizations operating today, it alone, is not and cannot be held responsible for organizational survival (Cerulo and Ruane 1998).

Earl, et al. (2010) define four categories of Internet activism; “Brochure-ware,” “Online Facilitation of Offline Activism,” “Online Participation,” and “Online Organizing”. In terms of internet usage, LPA and MAGIC involve both “brochure-ware,” in which information is disseminated online, and “online facilitation of offline activism,” in which things like the annual conference are planned and organized, but ultimately, the substance of the organizations takes place in-person and offline (Earl, et al. 2010). On the other hand, NOSSA is an example of “online organizing” or what has been termed an “e-movement,” in which all organizational activity occurs online (Earl, et al. 2010).

Disability Stance

It is common for one social movement to have an impact on new or future movements, such as the impact that the civil rights movement and the women's movement had on the gay rights movement and the disability rights movement (Meyer and Whittier 1994; Scotch 1989). One would think that having the influence of a larger social movement would help give credence to a smaller one, such as that seen for short stature. However, this has not really been the case.

NOSSA and MAGIC, however, reject any association with the disability rights movement. While NOSSA desired equal rights and equal participation, similar to the disability rights movement, leaders and members of the group did not view themselves as disabled. They viewed themselves as being short-statured activists, rather than activists for persons with disabilities. However, one respondent used the term “vertically challenged” to describe those of short stature, which is similar to the notion of “differently abled,” commonly used by disability rights activists (NOSSA Interview #3). For MAGIC, the goal of “normalization,” goes directly against the idea of disability rights, which seeks to celebrate, rather than suppress, different identities.

Distinct from MAGIC and NOSSA, is LPA, which is moving in the direction of a disability rights stance, especially considering the goal of “separatism” and celebrating the unique culture of people of (extreme) short stature (this is similar to the Deaf). While LPA most closely aligns itself with disability rights, there is not total agreement between members and leaders on the subject. Some LPA members are wheelchair-bound or have other issues and do consider themselves disabled; however, there are members who have very few functional limitations other than their lack of height, and do not view their short

stature as being a disability in and of itself. One practical application of a disability rights stance within LPA, however, is the accommodation of getting the built environment to more closely fit those of extreme short stature, such as the height of counters, automatic teller machines (ATMs), vending machines, public faucets, and gas pumps lowered to wheel-chair height, and accommodations such as pedal extensions in cars (Kennedy 2003; Roloff 1999; Trombino 2008; Van Etten 1988). While LPA shares many goals with the disability rights movement, having to identify as disabled is for many too great a price to pay for this alliance. This tangible need for accommodations while not wanting to be considered disabled is a dilemma that the organization will continue to grapple with for the foreseeable future.

While LPA comes the closest of the three organizations to aligning itself with the disability rights movement, the issue is by no means unanimously accepted in the organization. LPA's equivocal stance on a variety of issues, and ethic of personal choice, means that the entire organization may never be all on the same page about LPA's role in the disability rights movement. One notable quality of the disability rights movement is the fact that a variety of disabilities are represented by organizations that consider themselves within the disability rights context (Scotch 1989). While this seeming coalition-building might seem useful to propel LPA forward, the lack of coalition-building between short statured organizations calls into question whether it is realistic to assume that coalitions will be made between short statured organizations and broader organizations, such as those within the disability rights movement.

Turf Wars: Organizational Connection and Crossover – The Question of Creating Community

One question that has continued throughout this research is whether the three organizations under study here have had any connection to each other. As it turns out, it would seem that there has been little interfacing between these three organizations, which may help explain why there has been a lack of action beyond that at the level of the individual organizations.

One example of this is seen throughout the LPA newsletter, where there are brief mentions of the other organizations, including the Human Growth Foundation (HGF). It is hard to fully grasp the nature of the connection between HGF and LPA, especially given the following excerpt from a letter to the editor from a leader of HGF: “In the future, please contact us prior to printing information in your newsletter regarding our organization and the availability of our materials” (LPA Newsletter, Volume 34, Number 3, 1997: 4). This would suggest that the relationship was at best adversarial. And it is difficult to ascertain this relationship as HGF is no longer an active organization.

While I asked respondents about their knowledge of, and involvement in, other organizations dealing with short stature, the response was largely the same. They had heard of the other organizations, but did not really have anything to do with them. One participant said, “And I tend to know from these other organizations, well, the kid’s gonna adapt, and he’s going to blend in, and he’s going to no longer exist” (Jon; LPA Interview #2). This emphasizes the distinct goals and mission of each organization, and how these may be in direct conflict with the goals and mission of the other organizations.

While LPA President Gary Arnold claimed never to have heard of any of the other short stature organizations that I mentioned, he agreed that the organization could do a better job of coalition-building: “So, yeah, that’s an area of potential for us, you know, building relationships with groups out there where we might have some overlapping interests.” And Executive Director Joanna Campbell did not have very positive opinions about MAGIC, but said of NOSSA: “Um, NOSSA, the National Organization of Short Statured Adults, we think they’re great, and we refer a lot of people to them. Um, sometimes people like yourself, you’re just sort of shorter than average, but you don’t necessarily have a diagnosis of dwarfism or a skeletal dysplasia, so we, um, we do like them very much.”

What is clear is that there is not very much overlap between the organizations. It is the case in terms of these organizations that each organization’s members are members of only one organization. This may be in part because of the diagnostic categories that LPA and MAGIC employ, which are specific to each organization.

An illustrative case is the experience of Edna, a member of NOSSA. When asked about her relation to LPA, she explained:

Oh yeah! They don’t, Little People of America... doesn’t like... NOSSA. I don’t mean to interrupt, but there’s a lot of politics that go on. Like Little People of America doesn’t like me. They don’t really know me, but they don’t like someone like me... There’s a, um, a lot of, um, political infighting that is also a huge problem. I mean, you see this in all, um, groups that are fighting discrimination. But, you know, I, I’m looked at, at 4’8 ½” as quote unquote the healthy, taller short... So there’s, when I’ve tried to talk to Little People of America, tried to be involved with them, they, you know, even though it says, I think it’s 4’9” and below or 4’8” and below [it’s actually 4’10” and below], they really wanted nothing to do with me. So there’s a lot of political stuff like that, which I understand. But people feeling like their voices are going to get lost, in something, in a group that they see as not suffering as much... Yeah, yeah. Well, like at 4’8 ½”, when I’m, you know, proportioned and, you know, just a

variation... that it's looked at as, well, you don't really belong here. (NOSSA Interview #2)

Despite falling within LPA's height requirement, because Edna is proportional, she does not feel that she really fits into the organization, and the organization did not seem to have any problem telling her so. Therefore, because of her ostracism from LPA, she decided to join NOSSA, where she was welcomed with open arms (as a person of short stature).

Along with the minimal overlap between organizations, the organizations do not really communicate with each other. This lack of interfacing was described particularly well by one participant:

[E]ven within the odd groups... Instead of all banding together and saying, 'We might have different issues related to our short stature, and we might have, you know, you have more of this problem, I have more of this problem,' that there isn't a wide circle of things, we come, you know, we're not just, we're all out there clamoring for diversity, but yet, when it comes to this segment, at least how this organization [referring to LPA] is set up, there's not a celebration of diversity. I am, I am too quote unquote normal... There's like an, um, just like there's rifts in the Fat community, if somebody is quote unquote not fat enough. (Edna; NOSSA Interview #2)

When asked, people would comment that they liked a certain organization, or that they had heard of them, but that was the extent of it. One has to wonder if this isolation has had a negative effect on what these individual organizations are able to accomplish, and whether they would be more successful if they pooled their resources. If organizations with similar ideologies and goals such as LPA and NOSSA had combined forces, and MAGIC and HGF had combined forces, how would this have changed the landscape of short statured organizations? Would HGF and NOSSA still be in operation today if they had collaborated with another organization?

Unfortunately, we will never know the answer to this question. In all of the interviews with organization leaders, these other organizations were never mentioned until I brought them up. It seems clear, therefore, that all of these organizations feel that they exist on their own, that they are the only ones doing what they do. This might be true in light of each organization's particular views on height, but they are all organizations concerned with short stature, nonetheless.

A Lack of Activism

One question posed to participants was why there has not been more pointed activism on the part of people of short stature. This is not an easy question to answer, but several participants attempted to do so. One participant posited that the reason there has not been stronger mobilization by people of short stature is that, unlike racial and ethnic minority groups, such as African Americans, people of short stature do not have their own "literal" communities, as do the aforementioned minority groups, who tend to live in enclaves or common areas. She explained:

I think one of the logistical things is that, unlike, you know, unlike race, where, you know, it, because of many others, there's a planned community and everything, but, you know, so it tends to be groups that live together. You know, if you are, if you're African American, there were pockets of neighborhoods or a community where people tended to live. You know? Either because they were excluded from other places or because, you know, that was just a way of, you know, you're Black, you want to be in a Blacker [*sic*] community... Um, places that people sort of just stay together and support one another. But when you're short, you don't live in a short community. You don't say, 'You know what, the schools are good here, we've got a really strong short population.' [laughs] So we're just kind of everywhere. And that just, at a logistical level, makes it harder for people to band together. (Edna; NOSSA Interview #2)

This is consistent with the social movement literature that suggests that physical segregation – especially when considering certain members of the disability rights

movement, such as the Blind and the Deaf – can make it easier for groups to mobilize (Groch 2001; Wolfensberger and Tullman 1982).

Another reason offered by a member of LPA is that Little People tend to lead fairly independent lives, and this may be one reason for a lack of more visible activism on the part of people of short stature. Executive Director Joanna Campbell described:

I think that, um, one of the things I've noticed is that people within LPA, um, you know, you just get used to solving your own problems. And usually that means, you know, you get a stool, basically. Or you do some other sort of physical accommodation so that you can reach what you need to reach. And so I think people, individually, have just sort of done what they needed to do individually, to make their environment work for them, as opposed to, you know, a big collective group, say everybody in wheelchairs that are trying to make their environment work for them... It's like, we're just all used to solving our own problems, and our kids get very used to solving their own problems; getting a stool, learning how to climb shelving, whatever it is they need to do. So, I think that's why collectively we haven't necessarily joined together as a group effort so far.

According to a leader of MAGIC, she felt that, more broadly, there was less activism because people view the treatment of short stature as a cosmetic issue rather than as a health issue. This is one reason why the organization has pushed so hard for the recognition of their stance of “height as a proxy for health,” not only within the organization, but within the general public, as well.

While each of these potential answers to the question of the lack of activism reflects the organizations, themselves, it seems there is at least some awareness that these organizations have their work cut out for them. And raising awareness with both people of short stature and the general public is a key component of each organization. How successful they are at doing this remains to be seen.

Another reason for this lack of activism (especially in the case of Little People) may have been that, historically speaking, dwarfs tended to avoid each other, and coming

together has only been present in the modern era (Adelson 2005b). However, this does not explain why there has not been a proliferation of organizations for short stature as there has been for similar groups like the Deaf (see Appendix C). This may be purely a numbers issue. While there are 30,000 dwarfs in the United States (Little People of America 2009) and 8,000,000 short statured people, there are more than 30,000,000 individuals with various levels of impaired hearing (National Institute on Deafness and Other Communication Disorders 2010). Further, because the Deaf are not a visible minority – unless they are using American Sign Language (ASL) – they have actively sought each other out via separate schools, such as Gallaudet University, and other social institutions reserved for them (Rosen 2008).

A lack of a visible, cohesive community, a lack of perceived need on the part of individuals, and the view of treating short stature as a cosmetic rather than a health issue, may be three reasons for why there has been a lack of activism on the part of people of short stature. In particular, NOSSA pointed to a lack of participation by the short statured community as a reason why the organization failed.

Conclusion

It all started with a need to fill a void, one or a few people realizing that there was a niche that needed to be filled, a void in their own lives that they felt might benefit others, as well as themselves. For Little People of America, the MAGIC Foundation, and the National Organization of Short Statured Adults (NOSSA), that niche was short stature. And while the approaches of these three groups differ greatly, the subject is the same. Making life better for people of short stature, whether that means by celebrating difference and creating a unique culture, normalizing so that short children are no more,

or creating equality within the broader society, is really the key component to all three of these organizations. It is at times hard to see this when focusing on each organizations' ideologies individually.

In some ways, these groups represent a classic sociological problem: Do we focus on fixing the individual, or rather, focus on society as a whole? In the case of LPA and NOSSA, the focus is on society. And in the case of MAGIC, it is on the individual. While LPA and MAGIC have been successful, despite this difference, NOSSA was not successful, despite its view that society should change rather than individual short people.

Not only do we see the distinction between the way these groups act in terms of the individual and society, we also see how they act in terms of equality and difference. Feminist scholars have, for a long time, struggled with the distinction between equality and difference (Milkman 1986). In the case of these three organizations, the question is whether short and tall people should be treated equally or whether the differences that exist between short and tall people should be celebrated.

While every society has people that are different and stigmatized, and ours is particularly nasty about stigmatizing people, these organizations are three paradigmatic cases in how to use collective action to organize around difference; in other words, through these groups, we see how people deal with their visible difference in a society that is obsessed with appearance. LPA is a movement that celebrates difference, like other forms of identity politics and transforms the stigma of extreme short stature into an identity to be celebrated and preserved. NOSSA is equality-based, and suggests that there are no relevant differences between short and tall people, and society should treat people equally based on height. MAGIC is an equality-based movement, as well, although the

organization sees difference as undesirable and seeks to change it, accepting society's definition of what is "normal" and desirable, and changing one's body to fit that norm.

Here we see that equality and difference have both positive and negative functions. With difference, while there is celebration, there also tends to be the suppression or devaluation of other personal identities in favor of the identity that is being celebrated. With equality, sameness is emphasized, while any distinctions are negated and suppressed, and equality seeks to reinforce already existing norms and hierarchies of power that exist in society (Armstrong 2002; Wollstonecraft 1995). It would seem that equality may be more difficult to achieve than difference, and we can see this as displayed by the three organizations under study here.

All of the organizations fall victim to the pressures of society that exist outside of their organizations. LPA does this by using medicalization, having a medical advisory board, allowing doctors to have unquestioned membership in the organization, and providing free health consultations at the annual conference. MAGIC does this by using the rhetoric of health, and therefore medicalization, and constantly having to be on the defensive about using growth hormone in seemingly healthy children. NOSSA did this, inadvertently, in the fact that not all members of the organization felt that short stature was a determining factor in their lives, which mirrors the attitude of the general public, and was one reason for the organization's demise.

The question that does remain, however, is whether these three (now two) groups make up a bona fide social movement, or whether they are simply three organizations focused on the issue of short stature in three very different ways. One has to wonder if these groups could have been stronger in coalition building, however, given their

differing stances on a variety of issues, it is unclear whether they would ever have been able to sit across the table from each other amicably. For a social movement to exist, the groups that are a part of it cannot exist in isolation of each other. Not only do they fail to build relationships, rather, they create rifts that only seek to make shaky already tenuous ground (Snow, Zurcher, and Ekland-Olson 1980).

By bringing the issues of people of short stature to light, these organizations call a large part of our history into question. Nearly every President has been average height or above,⁸⁰ and nearly every President that has been elected since 1900 has been the taller candidate (Conrad and Potter 2004; Feldman 1975; Gillis 1982; Keyes 1980). And the average height of CEOs of Fortune 500 companies is 6'0" (Gladwell 2005) – and in general, tall people make almost \$800 per inch per year more than shorter people (Judge and Cable 2004) – so for those who claim that height does not matter, it clearly does. But to question whether such occurrences happen merely by chance, or are created via some deeply held social belief about the value of tall stature over short stature, would be to question the very fabric of our society, and history, in general (Adelson 2005b). And that is why it is so important to understand the organizations that are in existence to help make visible the plight of the short person, and elucidate the benefits and problems that come with being a person of short stature. By acknowledging height, we may fail to attend to the paucity of identities that people of short stature have, while avoiding height altogether fails to give credence to those who have experienced difficulties and discrimination as a result of their short stature. Unless the MAGIC Foundation has its way, the problem of short stature is something that will not go away any time soon. So it is important that we understand how people make sense of their identity, especially in an

⁸⁰ Only 14 Presidents of 43 have been under the average height of men in the United States, which is 5'10".

environment where some people and groups feel that the best thing to do is to get rid of that identity altogether.

Because so little is known about these organizations, there is fertile ground for future research. First, it is important to understand those who are of short stature who do not take part in these organizations. What about those people who may not fit into these organizations, for example, those with dwarfing conditions who are over 4'10" and those without conditions that are shorter than 4'10"? As medical technologies continue to proliferate, the question of how, why, and when we use these technologies will remain, and may become even more difficult to answer. As more groups find inclusion via disability rights, it will be important to pay attention to how these groups operate, both together and separately. As social movements come to rely more and more on the Internet, it will be interesting to see how social movement scholars adapt to such shifting sites of activism, protest, and change. We are currently experiencing a globalization of heightism: Newspapers report that some Asian countries have imposed height requirements as a condition of employment, fueling the demand for limb lengthening surgery (Dorf 2004; Smith 2002). This, too, deserves future study, along with the treatment of people of short stature in other countries outside of the United States. And finally, it will be important to follow the organizations that were studied here to see how they adapt, grow, and change in the future.

Appendix A:
Case Studies of Interviewees

Little People of America (LPA)

Case Study 1: LP adult joined LPA as a child

Adam is a 3'6" LP adult with Cartilage-Hair Hypoplasia,⁸¹ whose parents joined the organization when he was about 10 years old. His parents are AH, and he has one brother that is AH and one that is an LP. Adam's wife and daughter are also LPs, although they have Achondroplasia. He is employed in the entertainment industry, and lives on the West Coast. (LPA Interview #1)

Lana is a 3'11" woman in her 60s. She has Pseudoachondroplasia,⁸² and is from the Midwest. The rest of her family, including her parents and siblings, are AH. Lana has had many corrective leg surgeries to minimize bow-legging. She got involved in LPA when she was young, but did not attend a conference until she was in her teens because of the expense of going to the conference. Since then,

⁸¹ Cartilage-Hair Hypoplasia is a rare form of dwarfism, which "is characterized by short-limb dwarfism, fine, sparse, and light-colored hair, and hyperextendability of the fingers and wrists" (Adelson 2005a: 289).

⁸² Pseudoachondroplasia is typically diagnosed later than Achondroplasia and Hypochondroplasia, "when delayed walking or an abnormal gait is evident...Head growth and facial features are normal. Pseudoachondroplasia is associated with osteoarthritis and other orthopedic problems that often require surgery" (Adelson 2005a: 288-289).

she has been involved at all levels of the organization, although she has a desire to champion various types of disability-related causes, along with LPA. (LPA Interview #6)

Ashley is an Achondroplastic dwarf⁸³ in her 30s. She is 4'11". She is from the Midwest and attended LPA chapter events as a child, although she did not attend her first national conference until she was 20 years old. Ashley has gotten very involved in conference planning and hopes to be involved in "Growing and evolving LPA" and "Defining [the organization's] role within disability rights". (LPA Interview #11)

Brenda is a 4'2" woman in her 30s. She is from the East Coast. Her husband is an LP, who she met through the organization. She has one adopted and two biological daughters, who are all Achons. She has been a member of LPA since she was 10 years old. Brenda is very active in the organization, and has held a variety of positions at multiple levels. (LPA Interview #14)

Jack is an Achon man in his 30s, from the Midwest. His mother is an LP and his biological father is AH. He has an AH brother. His stepfather is an LP, and the person who really got him involved in LPA, even though he joined as a child,

⁸³ Achondroplasia is a disorder of the bone or cartilage, also known as a skeletal dysplasia. Achondroplasia is the most common form of dwarfism, "[R]epresenting approximately half of all cases of profound short stature. Achondroplastic dwarfism is characterized by an average-sized trunk, short arms and legs, and a slightly enlarged head and prominent forehead. Other distinctive features that include a relatively low or flat nasal bridge...and prominent buttocks and abdomen" (Adelson 2005a: 287).

along with his mother. Jack's mother and stepfather met at a LPA convention, and he has been an active member ever since. (LPA Interview #5)

Case Study 2: LP adult who joined LPA as an adult

Jon is an older man in his 70s. He is 4'8". His wife is also an LP. She has Achondroplasia and he has Precocious Puberty.^{84,85} While he is now retired, he worked in various state agencies throughout his life. Jon was born in the Midwest, and is now from the West Coast. He has been heavily involved in the organization, and he spends a significant amount of time per week, as much as a part-time job, working on things for LPA. He and his wife have attended the national conference regularly for the last 15 years, although his participation was "off and on" until he retired. He also considers himself a disability activist. (LPA Interview #2)

Monica is a 3'6" woman in her 60s with Cartilage-Hair. She is the youngest child in her family and the only LP, with "no history of dwarfism at all." Monica has had several corrective leg surgeries due to bow-legging. She became involved in LPA in her late teens or early 20s. Her husband is also an LP. Working for a large

⁸⁴ Precocious Puberty is when puberty takes place at an earlier age than is typical, and this can cause growth problems.

⁸⁵ Another common type of dwarfism, after Achondroplasia and Diastrophic Dysplasia is Spondyloepiphyseal Dysplasia (SED). SED is characterized by short stature, clubfeet, cleft palate, and a barrel-chested appearance (Adelson 2005a). Two other forms of dwarfism that are also commonly seen in LPA members are Osteogenesis Imperfecta and Primordial Dwarfism, although none of those affected are represented here. Osteogenesis Imperfecta is also known as brittle bone disease. Primordial Dwarfism is characterized by extreme short stature, along with all bones and organs being proportionally smaller than those of AH.

computer company, and being the only LP employed there, Monica advocated for changes that would make her workplace more accessible to LPs. She currently is employed with a state agency on the West Coast. Conference attendance for Monica occurs about once every five years, although she has a strong desire to help other LPs and give back to the organization. (LPA Interview #7)

Mary is a social worker in her late 20s from the Midwest. She is 3'8". She is a colorfully tattooed young woman with Diastrophic Dysplasia.⁸⁶ Her parents and sibling are AH. She joined LPA in her mid-20s. While she said she knew about LPA since she was a child, she "didn't want anything to do with other little people". She decided to attend her first conference because it was being held near where she lived and she figured she could easily leave if she did not like it. While her participation is mainly at the national level, and despite her initial concerns about joining the organization, she "has been hooked ever since" she attended her first meeting. (LPA Interview #4)

Greg is 4'11" and has Hypochondroplasia.⁸⁷ He is in his 20s. Of his AH family, he said, "Everybody is [AH]. I'm the only one [LP]. To my knowledge, I'm the only person with dwarfism in my family." He is from the East Coast. He and his parents were never recommended to LPA when he was a child. He attended his first national conference several years ago. Since joining LPA, he has attended the

⁸⁶ Diastrophic Dysplasia "is characterized by short-limbed dwarfism," and can sometimes include cleft palate, clubfeet, and other orthopedic problems (Adelson 2005a: 288).

⁸⁷ Hypochondroplasia, while similar to Achondroplasia, is a different genetic condition. Those with Hypochondroplasia tend to be taller and have less medical problems than those with Achondroplasia.

national conference every year. He described himself as being amongst the shortest growing up, but coming to LPA, he is one of the tallest. He said “[W]hen I’m in the real world, I’m short. But when I’m in LPA, I’m tall,” “I feel like Shaq.” (LPA Interview #13)

Teena is a woman in her early 40s. She came from an AH family, and did not join LPA until she was in her mid-20s, although she had heard a bit about LPA as a child. Teena is 4’6” and despite going to a variety of doctors, she has never received a diagnosis as to a reason for her short stature. She describes growing up in a small town where her height was not an issue, and not even realizing she was an LP until her boss gave her an article about LPA. But she said that coming to LPA was helpful for her self-esteem, to be around others like her. Her participation in the organization is mainly at the national level, and she hopes to continue with LPA to be an advocate for short statured people. (LPA Interview #15)

Case Study 3: AH parents with an LP child

Sandy is an AH woman, whose four year old daughter has Achondroplasia. Her husband and son are also AH, and there is no history of dwarfism in their family. Her and her family found out about LPA from an information packet they were given in the hospital, after her daughter was diagnosed as an Achon. Sandy’s daughter was diagnosed later than most Achon babies, and she blames this on

going to a large practice where she saw various doctors: “I believe, had I had the same doctor through the whole term of the pregnancy, it probably would have been caught prior.” They attended their first conference in Seattle, and take part in two or three activities a year, although they have to travel to another state, as their daughter is the only one with dwarfism in their immediate area. (LPA Interview #3)

Kristen is also an AH woman with a four year-old-daughter who has Achondroplasia. Her husband is also AH. They are from the West Coast. She and her husband joined LPA right after their daughter was born, and the 2011 conference was their first national experience. Because of where they live, they haven't been very active in chapter or district activities. (LPA Interview #12)

Case Study 4: LP Couple

Victoria and James are a middle-aged couple from the West Coast. They are both LPs, the wife being just under four feet tall, and the husband just over four feet tall. Victoria came from an AH family, and joined LPA as a child. James did not join LPA until he met Victoria, in his early 20s. The couple has one adopted daughter and two biological daughters, all three of whom have Achondroplasia. (LPA Interviews #9 and #10)

Case Study 5: International Member

Fran is the mother of a teenage daughter with Hypochondroplasia. They are not from the United States, and said that the LP organization in their country, which they are members of, is much smaller than LPA. Fran said that she and her daughter have found the LPA website to be particularly helpful. While she does not think that they will attend the conference every year – because of the distance and expense – Fran said that she hopes to attend every four or five years, as she views the organization as “vital” to her daughter’s life as an LP. (LPA Interview #8)

Case Study 6: Leadership

Gary Arnold – current President of LPA – is a middle-aged man with Achondroplasia. He was born to AH parents, who were told about LPA from their pediatrician. He went to his first convention when he was nine years old. Gary took a break from LPA between the ages of 10 and 20, and then became very involved after that. He said: “Um, but uh, then I’d say after, I was in college, I started recognizing that I wanted to be involved with that. Um, that kind of raised my awareness around diversity, when I was in college.” He started out writing movie and book reviews for “LPA Today,” became Vice President of Public Relations – a position he held for five years – and began his term as the President of the organization in 2012. While I was not told directly by Gary, I found out

from the newsletter that he is married to an AH woman. He works for an independent living center in Chicago, and considers himself to be a disability-rights activist.

Joanna Campbell is Executive Director of LPA. She, her husband, and son are all AH, and she has a daughter with Achondroplasia. Joanna found out prenatally that her daughter had achondroplasia. She said she always knew that some type of organization existed, and her sister received information about LPA from a friend of hers who was a nurse. They joined LPA when her daughter was just four months old [her daughter is 19 now], and have been members ever since. Joanna is one of three part-time people employed by LPA, and she has been in her current position as Executive Director for over five years.

MAGIC Foundation

Case Study 1: Parents with Young Children

Wilma is a very pretty, young looking blonde. Her son is six years old. He grew normally at birth, but fell off the growth chart at age two. He was diagnosed with GHD from a small pituitary gland. He started GH at four years old. He was on Humatrope, but was then switched to Omnitrope.⁸⁸ Wilma found out about MAGIC on the Internet, about one month before the conference, and jumped at

⁸⁸ Wilma's son had a problem with one of the preservatives and was switched to a different GH. Because of this, unlike most families, her son does not use one of the fancy injection pens, but rather, the "old fashioned" bottle and syringe application.

the chance to attend. This is her first conference, and she left her husband and son at home, and is attending by herself. Wilma described MAGIC as “priceless”, “liberating”, and a “community of resources”. She plans to attend the conference every year, and bring her son and husband next time. (MAGIC Interview #7)

Marissa is a petite blonde. She is 4’10”, and her husband, who is not present during the interview, is 5’11”. Marissa is the mother of a daughter that was born a “micro-premie” at 25-weeks gestation, who weighed just one pound, seven ounces at birth. Her daughter spent the first four months of her life in the neonatal intensive care unit. Marissa was warned by doctors that the early treatment her daughter was receiving would likely stunt her growth. While she took her daughter to an endocrinologist at the age of five, it was not until her daughter was severely bullied in 4th grade that she became very proactive and started exploring her options. At that time, her daughter’s final height was estimated at between 53” and 55”. Her daughter was diagnosed with ISS. While originally worried about the side effects of GH, after watching her daughter grow four inches in her first year on GH, she advocates that other parents of short children should consider GH treatment. Marissa found out about MAGIC on the Internet, about six months after her daughter began GH. She has attended one other conference, where her daughter met her best friend. Her daughter has been looking forward to spending time with her at the conference. Marissa’s daughter, who is 11 years old, will be on GH until she is 14 or 15 years old. Her daughter is also on Lupron, a drug that stalls the normal onset of puberty. Marissa said that she felt misinformed by the

public opinion on GH. She plans to continue to be involved in the organization as long as her daughter is on GH, and will leave their membership up to her daughter. Marissa said that MAGIC has helped her deal with her anxiety about GH, and has increased her daughter's self-esteem. (MAGIC Interview #1)

Tracy is a very well put together woman. It is clear by her mode of dress and demeanor that she is affluent. Her daughter fell off of the growth charts at age three, and they were sent to an endocrinologist when her daughter was five. At that time, an abscess was found on her daughter's kidney, and her internal organs were being crushed because there was not enough room for them. After a week stint in the hospital, and receiving a second opinion, her daughter was diagnosed as a late bloomer with ISS. Tracy found MAGIC on the Internet. Her daughter is 13 years old, and they have been involved with MAGIC since she was seven. They have been involved at various levels of the organization.⁸⁹ Tracy also happens to be the mother of Marissa's daughter's best friend. (MAGIC Interview #6)

Nadine is the mother of a daughter who was diagnosed in 2007, at four months old, with Optic-Nerve Hypoplasia. Her daughter is deaf in her left ear, has a Vitamin D deficiency, and Hypothyroidism. Nadine found MAGIC on the Internet in 2008, and first attended the conference in 2009. She has also started running half marathon and marathon races to raise money for MAGIC. (MAGIC Interview #5)

⁸⁹ To give more information about this would be a potential breach in confidentiality.

Judy has two daughters; 8 ½ and 6 years old. Her younger daughter was diagnosed with a Growth Hormone Deficiency at the age of two. Her daughter was sick a lot as a young child, and Judy switched pediatricians many times until she was able to secure a diagnosis for her daughter. Her daughter started growth hormone shots in 2007. Judy found MAGIC online and has held several walks to fundraise in support of MAGIC. Along with her fundraising, she has also been a division consultant. (MAGIC Interview #9)

Bonnie and Jake are a middle-aged husband and wife. They have two children; a daughter and a son, both middle school aged. They are very outgoing, and are very encouraging to other parents in the networking sessions. They exude a wisdom that the younger parents do not. They were referred to an endocrinologist when their son was nine years old. The endocrinologist conducted a GH stimulation test, which their son failed. He was diagnosed with Isolated GHD, and was started on GH shots in November of 2009. He grew four inches in the first year, and as his parents described, is now “indistinguishable” from his peers, as far as his height is concerned. Like other parents, they found out about MAGIC via the Internet. This was their second convention, which they considered to be the equivalent to their yearly family vacation. (MAGIC Interview #3)

Case Study 2: Parents with Adult Children

Amanda has a son who was diagnosed with Growth Hormone Deficiency as a child. He is now 29 years old. She did not know about the organization when her son was young. Amanda began volunteering at the Human Growth Foundation (HGF) and later moved to MAGIC. Her husband is a physician and she helped in his practice, so it was a natural fit for her to get involved with MAGIC, helping families navigate the insurance issues that inevitably occur with growth hormone treatment. The 2011 conference was her second year giving a presentation on insurance (MAGIC Interview #9).

Rod has a large family, and one of his sons was diagnosed with McCune-Albright Syndrome. He and his wife found MAGIC in its infancy and were present at the very first convention MAGIC held. Unlike most parents that currently find out about MAGIC online, he was told about MAGIC by hospital social worker. He and his wife have both been actively involved in the organization, he as a Board Member, and his wife as a division consultant. (MAGIC Interview #11)

Case Study 3: Adult

Candy is in her mid-twenties. She was diagnosed with Fibrous Dysplasia at five years old. She was the beneficiary of MAGIC's scholarship program. Attending the MAGIC conference was the first time she met someone with the same

condition she has, and she described MAGIC as her “new extended family”. In her time with MAGIC, she has worked as a division consultant. (MAGIC Interview #4)

Case Study 4: Honorary Member

George Chmiel is a 30-something who works for Merrill-Lynch. His business partner’s daughter was very sick when she was born, and was diagnosed with Panhypopituitarism. He saw how MAGIC had been helpful to his business partner and his family, and decided to run ultra-marathons to raise money for MAGIC. In his first run, he raised \$66,000. Ultimately, George’s goal is to raise one million dollars for MAGIC, and to raise awareness about the organization. (MAGIC Interview #10)

Case Study 5: Leadership/Founder

Jamie Harvey’s daughter was diagnosed with a Growth Hormone Deficiency in 1985. It took three years to get the diagnosis. Given this, she and the other founders sought to make the lives of other such families easier. Later, another of her children was diagnosed with McCune-Albright Syndrome. (MAGIC Interview #2; see MAGIC chapter for more information on how the organization started and how this founder’s personal experiences impacted it).

National Organization of Short Statured Adults (NOSSA)

Case Study 1: Officers/Board Members

Donna was serving as the Vice President of NOSSA when I spoke with her. She is 4'9". She has published a memoir based on her experiences as a person of short stature. She claimed that because of the book, NOSSA sought her out and asked her if she wanted to be a part of the organization. The organization had been in existence for a year or two when she became involved in it. (NOSSA Interview #3)

Mike is 5'3" and he is employed in a field that is very gendered. He was the main impetus in trying to create a support group that would provide help to people of short stature. He got involved in Short Persons Support (sPs) and then had a hand in helping to form NOSSA. Mike had served as the Treasurer and was interim Secretary when I spoke to him. (NOSSA Interview #1)

Case Study 2: Member

Edna is a professional woman, and she is 4'8 ½". She has published several books, one of which is a memoir based on her experience as a person of short stature. She claims to have found NOSSA after doing research for her book. She got involved with the organization on more of an advisory basis, and her

involvement in the organization seems to have always been in flux, although she was never involved as an officer or member of the board. Despite her fluctuating involvement in NOSSA, she did not feel any connection, and more adversity, with LPA, even though she fit within their height limit. (NOSSA Interview #2)

Appendix B:
Organization Comparison Chart

	Collective Identity	View of Enhancement Technologies	View of Reproductive Technology	Framing	Formal/Informal Organization	Involvement	Disability Stance	Fear of Eugenics	Evident-ness/ Passing
Little People of America (LPA)	Yes	Equivocal	Anti/Pro	Identity politics; Separatism	Formal	Annual Conference; Newsletter; Archives; Staff; Board	Moving in that direction	Yes	Yes/ No
Major Aspects of Growth in Children (MAGIC)	Yes	Pro	Equivocal	Normalization (Height as a proxy for health)	Formal	Annual Conference; Newsletter; Staff; Board	No	No	Situation-based; Evident-ness increased by parents/ doctors
National Organization of Short Statured Adults (NOSSA)	No	Anti	Anti	Assimilation (Equal Rights)	Informal	Online Only; Volunteer; Board	No	Yes	No/ Yes
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The Deaf	Yes	Anti	Anti/Pro	Separatism	NA	Culture	No	Yes	NA
National	Yes	NA	NA	Equal	Formal	Annual	No	NA	Yes/

Association to Advance Fat Acceptance (NAAFA)				Rights		Conference; Newsletter; Board			No
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Appendix C:

List of Short Stature and Deaf Organizations

Organizations for Short Stature/Growth Disorders^{90,91,92 93}	Organizations for Deaf/Hard-of-Hearing^{94,95}
Human Growth Foundation (HGF) ⁹⁶	Abused Deaf Women’s Advocacy Services
Little People of America (LPA) (and Dwarf Athletic Association of America (DAAA))	Alexander Graham Bell Association for Deaf and Hard of Hearing
MAGIC Foundation	American Society for Deaf Children
National Organizations of Short Statured Adults (NOSSA) ⁹⁷	Association of Late-Deafened Adults
Prader-Willi Syndrome Association ⁹⁸	Deaf Bilingual Coalition
Turner’s Syndrome Society ⁹⁹	Deaf Seniors of America
	Deaf Women United
	Deaf – REACH
	DeafHope
	DOVE: Advocacy Services for Abused Deaf Women and Children
	Global Deaf Connection
	Hands and Voices
	Hearing Loss Association of America
	National Association of the Deaf
	National Black Deaf Advocates
	Rainbow Alliance of the Deaf
	The Starkey Hearing Foundation
	US Deaf Cycling Association
	US Flag Football for the Deaf

⁹⁰ This list only includes organizations that are primarily for people with the conditions, and not organizations that are specifically for health professionals.

⁹¹ This list only contains organizations that are in the United States.

⁹² This list was compiled by the author using the Associations Unlimited online database.

⁹³ These organizations were found using the search terms “short stature,” “dwarf,” “dwarfism,” and “growth disorders”.

⁹⁴ This list only includes general organizations for the Deaf, and does not include centers, institutes, schools/universities, or religious organizations.

⁹⁵ These organizations were found using the search terms “deaf” and “hard of hearing”.

⁹⁶ No longer operating, although the author was unable to ascertain the reasons for the organization’s end.

⁹⁷ No longer operating.

⁹⁸ Not included in this dissertation because organizations devoted to a single condition were not used.

⁹⁹ Not included in this dissertation because organizations devoted to a single condition were not used.

	USA Deaf Sports Federation
	United States Deaf Ski and Snowboard Association
	United States of America Deaf Basketball

Appendix D:

Background on Human Growth Hormone (hGH) and Extended Limb Lengthening (ELL)

A Brief History of Human Growth Hormone (hGH)

Short stature is defined as height that is two standard deviations below the mean, or the lowest third percentile for age and sex. Using this definition, about 18 million Americans are short. In a very small number of cases, short stature is caused by pituitary insufficiency. Most cases of short stature, however, are idiopathic – that is, the pituitary gland produces normal quantities of growth hormone. It is in these cases of Idiopathic Short Stature (ISS) that the use of growth hormone has been most controversial (Conrad and Potter 2004).

In the United States, short stature has been devalued and stigmatized (Moneymaker 1989), and tallness has been celebrated (Cohen 2009). Numerous studies have documented prejudice and discrimination against short people in employment (Persico, Postlewaite, and Silverman 2004; Steckel 1995) and interpersonal relationships (Chu and Geary 2005; Graziano, Brothen, and Berscheid 1978). Taller people are more likely to be hired and promoted (Case and Paxson 2008), to be elected to public office (Gillis 1982; Keyes 1980), and to be perceived as attractive and competent (Jackson and Ervin 1992). Conversely, short children are more likely to be teased and infantilized (Law 1987; Sandberg and Voss 2002). The pervasiveness of “heightism” and the size of

the potential market of short persons eager to be treated have propelled efforts to develop a treatment.

Although the study of endocrinology and the pituitary gland began in the late 1800s and early 1900s, it wasn't until the 1950s that hGH was used to treat children with insufficient growth hormone (Tattersall 1996). During this period, hGH was taken from the pituitary glands of human cadavers. Growth hormone treatment was exceedingly expensive, and the supply was insufficient to meet demand.¹⁰⁰ In 1985, it became evident that some of the people treated with the pituitary-derived form of hGH (both in the United States and abroad) had contracted Creutzfeldt-Jakob Disease – the human form of Mad Cow Disease – a rare and fatal spongiform encephalopathy (Brown, Preece, and Will 1992; Cohen and Cosgrove 2009), and the pituitary-derived version of the hormone was removed from the market.

It was with what Conrad and Potter (2004: 188) called “fortuitous timing,” that synthetic hGH came to the market a mere six months after the cadaver-derived hormone had been removed. For more than a decade, scientists at Genentech had been developing a technique for synthesizing hGH using recombinant DNA. The new synthetic hormone, marketed as Protropin, soon received FDA approval for the treatment of growth hormone deficiency and chronic renal failure (Conrad and Potter 2004). Since the synthetic hormone could be manufactured in boundless quantities, pharmaceutical companies were eager to find new uses for the drug.

It was only a matter of time, then, before drug companies, seeking new markets for Protropin, would begin testing it on children with Idiopathic Short Stature; and

¹⁰⁰ During this time, maximum height allowed while on growth hormone was 5'0", in order to allow for as many possible children needing treatment to get it. In 1977, the cutoff was increased to 5'4" (Phifer 1979).

parents of children with ISS, determined to give their short children every advantage, would begin to clamor for treatment. In 1990, a national survey found that 94 percent of pediatric endocrinologists had prescribed hGH “off label” to children with ISS (Cutler, et al. 1996). Genentech worked closely with the Human Growth Foundation (HGF), a non-profit organization of parents, which advocated for research and treatment of persons with all varieties of short stature (Conrad and Potter 2004). The company also sponsored trips to schools by representatives of the Human Growth Foundation and the MAGIC Foundation, in which children were measured, and letters were sent to parents whose children were deemed too “short”, urging them to seek medical treatment.

As the 21st century approached, restrictions on prescribing hGH to children with ISS had eased. The 1997 Modernization Act permitted pharmaceutical companies to disseminate off-label information to physicians, provided that the information had been published in peer-reviewed journals. In 2003, the FDA finally gave its approval to Eli Lilly to market Humatrope to children with ISS who were in the shortest 1.2 percentile.

Treatment of “short normal” children, or children with Idiopathic Short Stature – “children who have no other known medical conditions” associated with their height (The Hormone Foundation 2010) – with hGH has been debated widely, both before and after its approval by the FDA in 2003 (Haverkamp and Ranke 1999; Visser-van Balen, et al. 2008). Arrayed on one side of the debate are some physicians, pharmaceutical companies, parents, and some advocacy groups, who emphasize the prejudice and discrimination that often accompany short stature. Short children, including those with ISS, they argue, are entitled to enjoy opportunities available to children of average height.

Increasing the height of children with short stature will lessen discriminatory treatment, increase opportunities, and enhance their over-all self-esteem and well-being.

On the other side of the debate are several pediatricians, bioethicists, and sociologists, who have questioned whether the benefits of hGH are sufficient to outweigh its risks and costs (Elliott 2003; Rothman and Rothman 2003). By now, there have been many studies of the effectiveness of hGH in patients with ISS, and they present a mixed picture. Generally, hGH tends to speed the rate of growth in the short run, but the extent to which it can increase height by the time the child reaches adulthood is unknown (Hintz, et al. 1999). In a multi-center study, growth hormone was shown to increase overall height by about two inches (Kelnar, et al. 1999). These findings have led some observers to question whether this modest gain is sufficient to justify the procedure's risks, including diabetes, increased pressure on the brain, and leukemia (Haverkamp and Ranke 1999; Physicians Committee for Responsible Medicine 2004). Moreover, hGH is a relatively new drug, and many of the risks, as of today, still remain unknown (Allen 2006; Grumbach 1988).

HGH is also costly. Treatment takes place over a three to six year period, and costs about \$20,000 per year. If the average patient grows two inches, the cost of hGH is approximately \$50,000 an inch (Conrad and Potter 2004). Because ISS is not officially recognized as a disease, most insurance companies do not cover growth hormone treatment, and parents must pay out of pocket. This creates a private market, in which hGH remains inaccessible to all but the most affluent patients (Conrad and Leiter 2004; Churchill 1994). In the future, it is possible that short stature may become a condition of

the poor, who will then bear the additional burdens of height discrimination. In this way, hGH may ultimately augment disparities between the rich and the poor.

As Kelnar, et al. (1999: 157) note, there is “no strong evidence hGH therapy improves [the] psychological adaptation of children with ISS,” and hGH may actually entail psychological risks. Conrad and Potter (2004) suggest that, by seeking hGH treatment, parents may inadvertently convey to their children that short stature is an undesirable trait, thereby adversely affecting their children’s self esteem. Decisions about using hGH would be less complicated were short children able to participate in the decision-making process. However, to be effective, children must be treated at a young age (pre-puberty), when they are not yet able to give informed consent to a procedure which has life-long consequences.

Finally, sociologists have called attention to the negative cultural consequences of hGH treatment. Growth hormone treatment is a consequence, rather than a primary cause, of heightism. However, the very use of hGH implies that ISS is an undesirable attribute that must be changed, and, in so doing, actually exacerbates the stigmatization of short stature (Conrad and Potter 2004). Some commentators have suggested other forms of treatment than growth hormone shots (Churchill 1994; Physicians Committee for Responsible Medicine 2004), such as psychotherapy (Allen and Fost 1990; Lantos 1994). However, this approach still takes the focus away from the social nature of the problem, suggesting that the solution is to make individual children taller to fit in or “normalize”, rather than changing the societal bias against short stature. Some activists and sociologists (e.g., Conrad and Potter 2004) have argued for de-stigmatizing strategies that focus on eradicating stigma and prejudice against short stature in society at large.

A Brief History of Extended Limb Lengthening (ELL) and Cosmetic Limb Lengthening (CLL)

While hGH is sometimes used in cases of dwarfism, specifically Achondroplasia¹⁰¹ (Ablon 1981), extended limb lengthening (ELL) is the more commonly used procedure (The Pediatric Orthopaedic Society of North America 2013).¹⁰² According to Frank (2003: 1407): “In successive operations, bones in the legs (above and below the knee)...are broken, pins are inserted, and while the limb is encased in an apparatus that resembles a bird cage, the bone is very gradually expanded during the protracted healing process.”¹⁰³ Put simply, the patient’s legs are broken and then stretched, usually at a rate of one millimeter per day. This procedure usually takes place during the teen years, but can also occur at earlier or later ages (Frank 2003).

The procedure had been used as early as 1905, but was not in favor. Early methods came with great risk and often resulted in amputation of the limb and replacement with a prosthetic. Limb lengthening came into greater use in the 1970s and 1980s with the development of the Wagner, Ilizarov, and DeBastiani methods (named after their creators) proliferating. ELL has not found as much favor in the United States, as it has in Europe and Asia, where discrimination based on short stature (height) is blatant and overt (Catagni, et al. 2005; Herbert, Herzenberg, and Paley 1995; Peretti, Paronzini, and Marzorati 1995; Watts 2004).

As is the case with hGH, the indications for limb lengthening have gradually been expanding. While originally used to treat dwarfism, more recently, ELL has also been

¹⁰¹ Achondroplasia is a bone disorder characterized by disproportionate limbs and short stature. It is the most common type of dwarfism.

¹⁰² Or hGH and ELL are used in combination with each other.

¹⁰³ Some people with dwarfism undergo lengthening of both their arms and legs.

used to treat children and adults of short stature who have no known medical or genetic conditions associated with their height (Catagni, et al. 2005). While ELL is usually covered by insurance for those with dwarfism and people that have limb length discrepancies, those who are simply short are considered to be engaging in cosmetic limb lengthening, which costs upwards of \$100,000, and is not covered by insurance (International Center for Limb Lengthening 2010).¹⁰⁴

Cosmetic leg lengthening is done at several institutions around the country, such as the International Center for Limb Lengthening in Baltimore, Maryland. Candidates include men 18 to 52 years of age less than 5'9", and women of the same age range who are less than 5'3". Costs include:

The initial consultation, psychological evaluation and surgery are not covered by insurance. The cost of lengthening both femora (upper leg bones) is \$100,000, which includes physical therapy for 3 months. The entire cost must be paid before the operation. You will need to pay for your initial consultation and initial X-rays at the time of the visit. The initial consultation and the X-rays will cost a minimum of \$1,110. Similarly, if you undergo the psychological evaluation, you will need to pay for it at the time of that visit. The cost of the initial psychological evaluation is approximately \$2,300. No refunds will be made for the initial consultation or the psychological evaluation if you are not accepted into the program. (Sinai Hospital of Baltimore 2010)

Further, having the leg braces that actually do the lengthening removed, costs an additional \$12,000. According to the International Center for Limb Lengthening (2010), "unplanned surgery occurs in approximately 25 percent of the cases and can cost between \$7,000 and \$50,000. The cost of treatment for complications is not covered by insurance because it is a result of cosmetic limb lengthening" (Sinai Hospital of Baltimore 2010).

For those who undergo the surgery for non-cosmetic reasons, one study explained that the patient undergoes four operations, at ages five, six, 10, and 12 years of age,

¹⁰⁴ This figure is for the surgery only and does not include pre- and post-operative costs.

adding between 18 and 23 centimeters (cm) in height, which is equivalent to between seven and nine inches (Peretti, Paronzini, and Marzorati 1995). However, other studies have suggested average limb lengthening of 4.4 cm, 7 cm, 15.4 cm, 16.7 cm average, with 20.5 cm for Achondroplastic patients and 10.5 cm for short normal patients (Aldegheri and Dall'Oca 2001; Catagni, et al. 2005; Price 1989). Most patients of short stature with no related medical conditions can gain about three inches in height from the procedure (Kita 2004). Any greater increase in height is deemed too dangerous.

Average treatment time is 29 months, or roughly, 2.5 years, but is undoubtedly longer if complications arise (Aldegheri and Dall'Oca 2001). These complications include, but are not limited to; wound infection, pneumonia, loss of joint motion, deformities, deep vein thrombosis (DVT), cardiac arrest, and death. According to Dahl, Gulli, and Berg (1994: 10), "The actual process of limb lengthening is very complex and has one of the highest complication rates of any orthopaedic procedure." According to Gross (1999: 1575), "[D]espite the technical advances over the past decade, for the patient the procedure is still too arduous for it to become routine."

While the use of limb lengthening surgery is less common than treatment with hGH, it has been even more controversial. Aldegheri and Dall'Oca (2001: 246) wrote, "We are convinced that surgical lengthening of the limbs is not the ideal method to achieve the objectives that short stature patients aim. It is indeed an invasive, dangerous, complex and long-term procedure; it is associated with a high degree of complications, as compared with other surgical procedures." It has also garnered some criticism from persons who have had the surgery. For example, a short man who had the surgery remarked that it is 'an act of aggression against your own body' (Kita 2004: 135).

Another was quoted as saying: ‘I don’t think anyone can break both legs and come back 100 percent’ (Kita 2004: 146).

Yet, some doctors promote its use, reifying the notion that short stature is an individual problem, rather than a societal one. Catagni, et al. (2005) said, “Our results were gratifying in that the patients considered their stature as normal and they could shed their inferiority complex” (1405).¹⁰⁵ And Price (1989: 515) said, “Based on the results...it is my conclusion that limb lengthening for achondroplasia by this technique should now be routinely performed in the United States.”

¹⁰⁵ That is, where, given the gain in height, “normal” height is actually possible.

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