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THE SOCIAL CONSTRUCTION OF DISABILITY AND THE MODERN-DAY HEALER

BY

JENNIFER ANNE VANDERMINDEN

BA, University of Vermont, 2006

THESIS

Submitted to the University of New Hampshire

In Partial Fulfillment of

The Requirements for the Degree of

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In

Sociology

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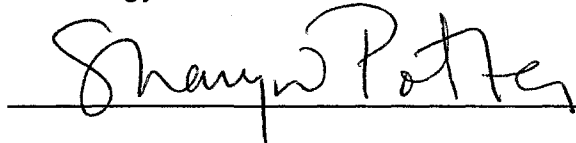
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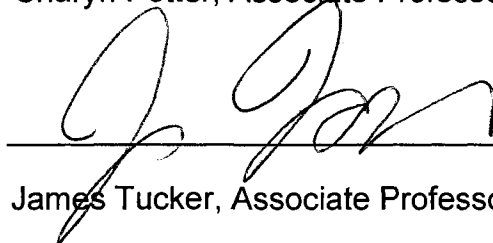
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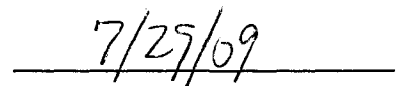
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Date

This thesis dedicated to Mackayla.

I would like to acknowledge Ramón Cuevas for welcoming me into his community and allowing me inside the world of CME therapy. In addition I would like to thank Linda Blum for her mentoring through this process and her comments on the many drafts of this thesis. Her insights and expertise were vital for the successful completion of this thesis. Finally, I would like to thank my parents and Collin for their encouragement, assistance, and unconditional love.

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ABSTRACT

THE SOCIAL CONSTRUCTION OF DISABILITY AND THE MODERN-DAY HEALER

By

Jennifer A Vanderminden

University of New Hampshire, September, 2009

Ramón Cuevas is a physical therapist and the founder of Cuevas Medek therapy (CME), a physical therapy for children with severe physical impairments. Since creating CME he has taught and practiced throughout the world. Families bring their children to see Ramón in his Chile office and elsewhere around the world to see him for therapy. I have conducted in-depth interviews with parents and Ramón, more than five weeks of participant-observation, and analyzed various online materials related to CME. I found that the community that is formed around these families and Ramón provides an excellent example of how disability is constructed in the social context. Secondly, I examined the relationship between Ramón and his clients, finding that through his close relationship with families and his charisma, he is able to successfully maintain this community which normalizes disability. This thesis adds to the growing literature on the social construction of disability and the field of knowledge on non-mainstream healers.

INTRODUCTION

I am sliding backwards on my knees, Ramón has Mae walking on stilt-like boards (vertical boards where she has a small surface to stand on and is elevated about three feet in the air). It is my job to move the vertical boards the length of her stride. This is challenging for me because I am uncoordinated; in another situation, I might think to complain that I have rug burn on my knees and my muscles are sore. Here, I think better of it, as Mae is walking on boards as an exercise with Ramón to enable her to walk. Currently, she is unable to walk independently and her mother and I have brought her to Chile to see Ramón, the founder of Cuevas Medek Exercises. While I move the boards step by step, Ramón is helping Mae to balance her body through holding firmly onto her ankles; otherwise she is standing and balancing alone. Her mother, Kate, walks next to us with her arms up, waiting and hoping that Mae does not fall. We make it across the room without incident; Mae is looking down at me, smiling because she knows that she has made it, her Mom reaches over to help her down from the stilts. A soft knock on the door indicates that Mae's 45 minutes are up and it is time for another child to see Ramón. We rush around to get Mae back into her chair, to clean the mats, put them up, and lastly put our shoes on before leaving for the waiting room. Mae will return in two hours for her next session. In the small waiting room a mother with bright red hair, Lucy, smiles at us.

Her daughter, Daisy, is going to see Ramón next. As Daisy looks brightly at Mae from her stroller, her mother comments it is because Daisy looks up to Mae, this makes Mae smile also. We leave the office; it is time to wait for the next session.

Mae is one of many children who travel to Chile to see Ramón; in fact families travel from all over the world to come here to see Ramón. Ramón's clients are children who have severe biological impairments. Why is this of sociological interest? Ramón has successfully created not just an international client base, but also a community in which disability is normalized. In addition to highlighting the fluidity of disability, this thesis takes advantage of an opportunity to examine the practitioner/patient relationship under such distinctive circumstances. This small community gives us an opportunity to see the fluidity of disability in two different contexts, emphasizing that disability is a social construction. This thesis will proceed with the argument that disability "is neither 'natural' nor essential but rather that it is socially produced" (Marks, 1999, p. 78).

This thesis utilizes the unique opportunity to see how disability is fluid and differently defined and understood by setting. In addition, this thesis employs sociological research to better understand the community of families that is formed around Ramón that serves to normalize disability. I will explore what enables him to form this unique organization, mainly through his close relationship with his clients and his charismatic qualities. This thesis also attempts to help fill a gap in the literature on disability, specifically from a sociological perspective.

While there is a recent interest in literature within sociology focusing on disability today, most of the previous work in the field of disability falls within one of two spheres: applied or narratives. With respect to children, the most common disabilities literature is applied, guiding parents and educators on “how to” raise or educate children with disabilities (Barsch, 1968; Miller & Bachrash, 1995; Spock & Lerrigo, 1965). In addition, literature often focuses on how to advocate for a child, how to navigate through life with a child with disabilities, or how to deal with day to day issues that children with disabilities confront (Nisbet, 1992). Narratives or stories depicting individuals’ life events or experiences are becoming increasingly popular in many fields (Charon, 2004), especially within the field of disabilities studies. Disability literature, namely the *Disabilities Studies Reader* (Davis, 1997), the *New Disability Studies History* (Longmore & Umansky, 2001), and many others not mentioned here, emphasize the individual's experiences with disabilities through narratives (both historical and current). *Disability, Self, and Society* incorporates personal narratives with a discussion of disability within society and how society constructs what is right and wrong, normal and disabled (Titchkosky, 2003).

Sociological research on disability includes work on the social construction of disability (Albrecht, 1976), on the interface and overlap of the disabled and able-bodied (Tregaskis, 2004), gendered parenting of children with disabilities, as well as the distribution of disability within society. While there is much theorizing about the fluidity of disability, specifically temporary disability and aging populations, few researchers have had the opportunity to report on the contrast

of a society where in one setting the norm is “able-bodies” and the other disability. In this thesis, I contrast two environments: the first in which the norm is characterized by able bodied, mainstream, fully functioning children, and the other in which the norm is a child confined to a wheelchair, as is the typical case for children or clients visiting Ramón for therapy. One parallel example is the work on the deaf in Martha’s Vineyard. Groce, a medical anthropologist, looks at a community in which sign language is a standard form of communication; where the deaf were not disabled (1985). Groce uses an ethno-historical approach arguing that, “In Western Societies “handicapped” individuals have been expected to adapt to the ways of the nonhandicapped. By the perception of a handicap, and of its associated physical and social limitations, may be tempered by the community in which it is found” (Groce, 1985, p. 51).

This thesis is broken down into two main parts: the social construction of disability and the “charismatic healer” relationship with clients and community that is formed as a result. Using the social construction framework, this thesis aims to show what life is like for a child with severe biological impairments in two different environments: at home and abroad. The second half of this thesis addresses Ramón as a charismatic healer within the community that he (with the children and families) is able to create and recreate.

Introduction to CME therapy

Cuevas Medek Exercises (CME) therapy to the untrained eye looks similar to typical or conventional physical therapy; in fact, during the first few weeks I

was exposed to CME therapy through a highly trained CME therapist, I was unaware that the therapy was any different than physical therapy typically done with children in the US and elsewhere. One mother in this thesis, Rita, participated in CME therapy with her then four-month-old son for months, watching therapy and engaging in “home therapy” prior to learning that this therapy was fundamentally different than what most other children receive. Her CME therapist was working in Toronto through the Canadian Federal public health care system. CME International head office is located in a large office building in an upper-class neighborhood in Santiago, Chile. This office is where Ramón practices six months of the year and where he calls home. For the rest of the year, he travels throughout Europe, North, and South America seeing clients in rented or borrowed offices, public buildings, and even out of private homes and basements. For the purposes of this thesis, I will only concentrate on Chile as it is the most significant location for his community of followers.

The office building is connected to two hotels: the Boulevard suites (for long term stays) and the Marriott Hotel (for short term stays) through the main lobbies and an assortment of other professional offices. Many of Ramón’s clients reside in these two hotels for the duration of their trip to see him for therapy. Some families, if staying for 6 months or longer, will rent or even purchase houses nearby. If families stay at one of these hotels, they can literally access Ramón’s office without setting foot outside. In addition, these hotels offer grocery shopping services, laundry, Internet access, and an assortment of other useful services. On the fifth floor of the building is Ramón’s office. Clients and families

ring a doorbell to be let into his small office, are prompted by Ramón's daughter, Claudia, or are simply just let in by another child's family if Claudia is out (which is frequent).

Ramón's office looks similar to any other professional space: there are four chairs for the parents or children (if able), though most children come in strollers or wheelchairs. In the waiting room, there is a bathroom, a refrigerator, and a microwave. Claudia's desk is in the far left corner of the waiting room, and often, while she is on lunch, you can find one of the mothers there using her Internet and desk while she waits for her child's next appointment. There are three rooms in Ramón's office aside from the waiting room: one for therapy (Ramón's main office), one empty office for visiting therapists or in some cases for children napping between sessions, and a third in which Ramón's son, John, works. Ramón's son is currently studying Psychology and shadowing his father as he hopes to follow in his footsteps someday.

On my second trip to Chile, Maybe (pronounced Mai- be) a Venezuelan speech therapist, was visiting to work with Ramón's clients for a week and a half. Most of Ramón's clients choose to see Maybe and her airfare was split between the parents whose children were seen (in addition to her charge per hour for therapy). During her time in Chile, she stayed with Ramón and his wife, and practiced out of the extra office space. On other trips, when the extra room is vacant, one mother would bring her child in there for feeding (through a Gastrostomy tube) or for naps in between sessions.

Inside the room for therapy, Ramón sits on the mats with the children in the center of the room. Sometimes they begin by stretching and other times they get right into therapy. The back wall of the room is covered with mirrors. In front of the mirrors there is a table for therapy with very young children (I have never actually seen Ramón or any other therapist use this table), a stereo for music, a handful of toys (mostly toys that make noise to distract very young children), and a small, dark green leather couch. There is a single sliding door to enter and exit Ramón's office.

Ramón does not use any complex equipment. His equipment consists of wooden boxes, boards, sticky cloths (like drawer liners to keep the boxes from sliding) and the occasional bouncy ball. There is a full wall of shelves on the far side of the office where the boxes and boards are kept. Throughout the session it is common for Ramón to change boxes and boards, sometimes with the help of a parent or whoever is in the room. Ramón takes notes on plain white paper about each of the children, sometimes during a session. He documents their progress (or lack thereof), including which exercises they performed and how many times. On the window ledge you can nearly always find a mug filled with steaming tea, or empty, ready to be refilled by the next person to offer.

Ramón maneuvers with his clients depending on their ability; with one child he walks her straight across the room just holding her ankles, and yet with another he works on him standing up with his hands firmly on his thighs. CME therapy and other physical therapies are different at the theoretical core, the main difference being that through the movements, he initiates triggers in the

brain for movement. His theory is that there are parts of the brain that have not yet received signals (or are asleep) and if he can initiate those signals through physical movements then perhaps the brain will remember. Ramón often says: "Ok brain, take a picture." I will go into greater detail on the primary differences between CME and classical therapy later in this section.

At the start of each session, there are very informal greetings; for example: "Hello again Ramón, is Alex feeling better?" or "How is your wife?" This is not surprising because most of these parents and children see him two or three times a day. Depending on the ability of the child, Ramón can see a child for up to four sessions a day. When visiting Ramón in Chile, for example, the child I accompany, Mae, sees Ramón three times a day, every day. If she is doing really well in therapy and there is a fourth space that day, Ramón will ask her if she would like to continue. In most cases, the interactions between Ramón and his clients are very casual. Often parents will give an update on the child on their health, attitude, or just what they have been up to in general. Some parents enter the room and hurry to set up the boxes and mats, others casually bring their child to the mat to sit or lay near Ramón and they take a seat on the green leather couch. One mother, Rita, can often be found with a snack sitting with her feet up on a chair at Ramón's desk. The amount of involvement of the parent seems dependent on the age of the child and also on the parents' personality and comfort level. Older children require a greater amount of spotting and assistance from the parents as it is more difficult for Ramón to maneuver them, but also to safely catch them in the case of a fall.

During some sessions the parents put on music to distract the children and in others the parents sit aside. Therapy sessions with children can sometimes be tense for the parents, as they want so badly for their child to succeed. One parent, Lucy, told me it is hard for her to sit still, that it was almost as if she could will her daughter to walk. She is often found sitting with her legs up on the chair with her hands beneath her or sitting in the waiting room while her daughter is in therapy.

Who is Ramón Cuevas?

Ramón Cuevas is a Chilean native who graduated from the University of Chile in Santiago in 1969 with his physical therapy degree. In 1971, he began the creation of Cuevas Medek Exercises (CME) therapy. Complementing his physical therapy training, he was certified in Acupuncture in Montreal, Canada. Ramón is married and has three children (two sons and one daughter), and a dog. Ramón began his career in Physical therapy in Venezuela working with children with Down syndrome. He described this move as follows: “In my last year I was able to go outside of Chile to develop my insight because I felt Chile was too traditional, too rigid to develop [his physical therapy career] and after one year of graduate [school] one of my coworkers from this University told me that there was a position available in Caracas, Venezuela. Here my story begins.” His practice is described in his words as “an eclectic cocktail of my knowledge.”

During his practice of this type of therapy he began to wonder if there was a better way to initiate movement and develop neural connections for these

children, and he began to develop a new form of therapy. He asked the permission of the parents of the patients with whom he worked to try a new type of therapy and started the beginning stages of developing CME therapy while living in Caracas, Venezuela. Once Ramón established himself as a physical therapist and creator of a new therapy, he was able to move back to Chile and begin practicing there. He then moved to Canada to practice for nearly a decade, and then moved back to Chile. Moving his practice from South America to North America allowed Ramón to create a client base across continents.

Ramón started traveling to administer therapy to children in the 1980s. He went to Toronto, Canada upon the request of a family for one week. At the end of the week in Toronto, he went to another home upon the request of another family to see their daughter, to see if he could help. This trip is when he shaped the idea that he could develop an international client base. He asked another family from Toronto to come see him in Chile for their son to receive his therapy; they agreed, and Ramón's first international client came to Chile. Between these two families, those who Ramón visited in Toronto and the first client family to travel to Chile, is how the word of mouth about CME and Ramón began. Today, Ramón has clients coming from countries all over the world, including many countries in South America, North America, Europe, and Australia. To date, Ramón estimates that he has seen over 4,000 children in his physical therapy career and trained 750 physical therapists from Israel, Brazil, Argentina, Mexico, Trinidad and Tobago, Montreal, London, Australia, and Chile.

Due to the cost of coming to Chile and seeing Ramón multiple times a day, it is essential that Ramón's clients have personal means of wealth or connections to access to money for therapy. All of the families (except one) that are in Chile seeing Ramón are necessarily financially sound. The costs of air travel, housing, and therapy make it so that only those of secure economic well-being or fundraising prowess are able to afford such therapy. These families often have learned about Ramón through other therapists or through online research, attesting to the educational status of many of the parents of this group of people. While this group is by no means representative of the population of children with physical impairments and their families, this sample is representative of Ramón's clientele.

What is CME therapy?

Cuevas Medek Exercises is essentially physical therapy practiced from a different approach than other types of therapy. The acronym MEDEK comes from the Spanish phrase "Metodo Dinámico de Estimulación Kinesica, translated into English as "dynamic method for kinesthetic stimulation" (Cuevas, 2007). Ramón defines Cuevas Medek Therapy as:

"...a pediatric physiotherapy approach based on dynamic challenging exercises manually applied for children affected on their developmental motor functions. This approach provides very concrete guidelines to stimulated babies in a totally safe way, starting from two months of age to many years after birth"(Cuevas, 2007). CME therapy can potentially treat children with any developmental disability caused by Cerebral palsy, Hypotonic conditions, or motor-delayed condition caused by any non-degenerative disease (Cuevas, 2007). "

Ramón has worked with children up into their teenage years. Ramón trains other therapists in CME therapy during his travels six months of the year. There are four levels of CME practitioners, all trained by Ramón (a level four instructor). Therapists practicing CME can be found in the US, Canada, Europe, Argentina, and elsewhere. While therapists practice CME therapy during the course of therapy with a child, it is typical for a therapist to recommend the child visit Ramón, whether in Chile or abroad. The purpose of seeing Ramón (instead of other CME therapists) is to advance the therapy stage or to see if perhaps he could improve the child's mobility in ways the local CME therapist could not. Ramón encourages the "tough cases" that are difficult for other therapists to visit him in Chile. This will be further discussed in the case of Rita's son in detail in part III.

While CME therapy(to a person unfamiliar with the intricacies of physical therapy), looks much like any other type of physical therapy without the external supports (e.g., walkers, splints, etc.), according to the founder, Ramón Cuevas, CME is in direct contrast to classical approaches to physical therapy. For the sake of this thesis I will contrast CME with Traditional (NDT) therapy that is widely used in the US, Canada, and also worldwide. The most well known physical therapy applied to children with disabilities, neurodevelopmental treatment (NDT) was developed in 1943 by Bobath and Bobath (Hong & Howard, 2002).

Ramón points to a few main ways in which CME is different than traditional NDT physical therapy. One of the core differences is that CME rejects

the use of external supports, such as splints and walkers. Instead, Ramón intends “to pose a challenge to the child’s brain, which must then create the appropriate response from inside” (Cuevas, 2007). In addition, CME therapy can be exercised regardless of the emotional status of the child, while in classical approaches, if the child cries the therapy session is typically terminated. When considering a child’s muscle tone, classic approaches generally will not place a child with hyper tonicity or severe spasticity in the standing position. Conversely, CME therapy practices the exact opposite. CME therapy does not require a physician’s diagnosis of a child’s condition, but rather seeks to listen to the parent’s interpretation of the limitations of their child’s development and movement.

After illustrating the technical differences in the CME approach and the classic approaches, it is important to further discuss additional differences, perhaps more obvious ones. Parents and clients have to travel to see Ramón; if he is traveling near their home, it is most likely for a month or less, and his sessions are quite competitive to attend. When seeing Ramón, the schedule is often intense and unpredictable. In addition, the interaction with Ramón is typically more relaxed in Chile than when visiting other therapists and doctor’s offices. In highlighting these differences between CME therapy and mainstream physical therapy, I attempt to both paint a picture of how this therapy works and what it looks like, and also to assist the reader to understand why parents are seeking CME therapists (especially Ramón) instead of employing classical therapy.

Methodology

This thesis consists of a collaboration of three methods in order to gain a more complete understanding of CME and the community that is formed. Three main methods were employed for this thesis: participant observation (>5 weeks), interviews (ten families in total), and use of online materials. I received Institutional Review Board (IRB) approval through Human Subjects at the University of New Hampshire prior to conducting this research in December 2007. Those who participated in this study were all the families that were available during two of my four visits to Chile (N=10; 9 families and Ramón).

I believe that ethnography, and more specifically interviews and participant observation comprise an appropriate strategy for studying Cuevas Medek therapy (CME) and Ramón. It is important for this sample of people that the researcher is a part of the group, in order to fully understand not only why and how these parents are following Ramón, but also the community this small group creates. During my participant-observation, I often heard parents of Ramón's clients and others mention that they are a delicate population who are often taken advantage of (I will elaborate on this in the doctor-patient section). In some cases, these parents seemed cautious of outsiders. Coming from my unique position of having spent countless hours caring for and mentoring a child with Cerebral Palsy, including crawling on the floor with her during therapy as well as additional experiences in my past (and present), allowed me to gain the trust and respect of the parents and children in Ramón's therapy community.

The in-depth interviews allowed me to understand how parents came to see Ramón, what resources enabled them to do so (for example: personal wealth, community support, etc.) and some background information on the family and child and his/her disabling condition. Most importantly these interviews offered me insight as to how being in Chile is similar or different to being at home, how daily lives are different, and what client and family relationships with Ramón are like. As this research is emergent, the questions that I asked were merely a guide for the conversation, and in many cases the parents being interviewed elaborated on stories and the like.

Importantly, through my relationship as caretaker of the child (Mae) that I accompanied in Chile, I found that I was readily accepted as part of the group. In Shapiro's *No Pity*, the first line of the introduction is "Nondisabled Americans do not understand Disabled ones" (Shapiro, 1993, p. 3). This statement underscores the notion of being a part of a group, being an insider or one who understands an individual with disabilities even if they are not themselves considered disabled. For children, the main actors in this group are often their parents as they themselves are still very young. I was able to access and gain the trust of the children and adults alike in this exclusive group through Mae, as I had already been on three trips prior to conducting interviews (two in Canada and one in Chile for a total of five), accompanying Mae and her mother to see Ramón for therapy. Many of the mothers assumed I was Mae's mother or older sister prior to our introduction.

I attribute the full access and acceptance of some of the mothers to the fact that they knew on some level that I could relate to their experiences as I have spent a great deal of time with Mae as well as accompanied her to see Ramón. For one year (2006-2007), I was employed as a one-to-one aide for Mae in her mainstream public elementary school. During that time I became very close with Mae and we continue to keep in touch since my departure for Graduate school. As we bonded, her parents and I have a relationship in which, when they need help, I am often asked to assist with her. I often take her for the day or weekends for quality time and to give her parents respite. Hence, I have attended many of Mae's therapy sessions and been on numerous trips with the family.

The participants in this ethnography were sampled based on those that were available at the time of my trips (March and May 2008). All the parents (and families) whose children were receiving CME therapy at the times I was in Chile agreed to participate. This is a relatively small number because of the frequency of appointments with the same children, Ramón works with most of his clients in 45-minute sessions ranging from one to four per day. The average number of families attending Ramón's intensive therapy in Chile in a week is approximately five but changes both in Chile and also in other countries (in the United States and Europe, Ramón is far busier than in Chile and some months are much busier than others).

Interviews

The interviews were conducted in Santiago Chile and range from 35 minutes to approximately 3 hours and were audio recorded. I interviewed with nine families and Ramón. Data is reported using pseudonyms for children and their families. The children in this study are fairly homogenous in the severity of their biological impairments. None of the children are able to walk or stand independently, few were able to speak, and their ages range from two years of age to eleven years old. The families are from the United States, Canada, Israel, and Argentina (Note: none of these clients are Chilean). Regarding their socio-economic status and financial means, all but one of these families are able to come to Chile either through personal or familial financial means. One mother was actively fundraising on the Internet and in her hometown and able to raise enough money to travel and live in Chile.

I contacted Ramón in advance of my trips to ask his permission to use his office space for interviews and also for time to interview with him. He then told the parents who would be present during my visit that I would be there conducting research and that they were encouraged¹ to speak with me. As the office space is small, I was able to ask the parents as they brought their children in and out of therapy if they would mind doing an interview; in addition I observed

¹ This may emerge as a limitation or a potentially important aspect of the data collection. At least one of the mothers was initially reluctant to talk with me and strongly encouraged by Ramon. This gave me the impression that she felt Ramon would be disappointed in her if she refused, though he had no way of knowing what she said during the interview.

the interactions within the office (phone calls, video conferences, conversations among mothers, etc).

The questions that I asked the parents (nine mothers and two fathers) were about what their expectations were in seeing him, if they had traveled for other therapists or medical purposes in the past, what types of supports are necessary for this extensive travel, how daily life differs in Chile or while visiting Ramón from life at home, and many others. A copy of the interview schedule is in appendix A.

Participant Observation

I was involved with this community prior to the onset of this research project, therefore gaining access to the office and rooms in which the families have therapy, or wait for therapy was very simple and involved disclosure of my project and consent on the families' behalf. The participant observations include (but are not limited to) watching and spotting children in therapy sessions with Ramón, conversing in the waiting room, going out on social events with mothers of children, and running errands with mothers. The main focus of the participant-observation is to document the daily routine of Ramón and his clients, their interactions, and the day-to-day lives of the families who are visiting Ramón. All of the interviews took place in Ramón's office building or in the adjoining hotel. The adults and children were informed that I was researching CME therapy and all signed consent forms (verbal or physical assent for the children). Ramón was more than happy to have me observe all of his therapy sessions and the events within his office. He appeared excited that a researcher had taken interest in him

and I think that there was a feeling among some of the mothers that this is an opportunity to get the word out about CME therapy. There was only one mother that was reluctant to speak with me and she attributed that to her time constraints.

Online Materials

Online materials emerged during my stay in Chile as an important aspect in the lives of these families and therefore of this ethnography. In discussions with parents many indicated that the internet was a very important aspect of their lives either through blogs, a source of information on disabling conditions, to stay in touch with loved ones, and for an assortment of other reasons. In addition, Ramón's website provides a wealth of information on CME to these families.

The internet plays an increasingly important role in the dissemination of information (Cotten & Gupta, 2004; Jadad & Gagliardi, 1998), particularly medical and therapeutic in this case. In addition the internet enables access to an online community for advice and support, whether through blogs and support groups or through Skype (an online communication center in which you can make video and voice calls) and AOL Instant Messenger, which both enable individuals to stay in touch with family and loved ones for little or no cost. Since the Internet is an important tool for these families for gaining information and to communicate, I will include the analysis of online materials in this ethnography to inform my findings.

PART II-THE SOCIAL CONSTRUCTION OF DISABILITY

What is Disability?

Disability is fluid; it changes in time, space, culture, and location. While that is the central concept of this thesis, an important question that needs to be answered is: What is disability? The term “disability” itself is disputed as being both an acceptable and an offensive term. Titchkosky argues that using the term “person with disabilities” as a reminder that they are “people” first is a reflection of the “sorry state of affairs of living in a culture whose conception of people is such that ‘disabled people’ do not quite fit, and the contrary thus remains something of which others need to be reminded” (2003, p. 24). Due to the negative connotations associated with the word “disabled,” many people take issue with its use (Russell, 1998). Others argue that labels such as children “with a disability” or “person with a disability” put the person before the disability, while others feel that such terms indicate that disability “is not quite a part of personhood” and thus not part of the self (Titchkosky, 2003, p. 24). None of these labels have been widely accepted and it is evident that a new vocabulary should be formed. Other terms have been established, such as differently challenged (Smart, 2001) and differently able. While I am not entirely comfortable with any of these terms, I have chosen to use “person with disabilities” as I found that among the community in which this ethnography was conducted this was one of the more acceptable terms.

Defining disability is contentious and based mainly on two frameworks: the medical model and the social model. The medical model of disability sees the person “only as a patient in the context of the medical setting” (Shapiro, 1993) and treats the disability or illness as scientific and treatable at the individual level (Marshall, 1998). The medical model of disability views the illness or disability as originating from within the body, a malfunction that the afflicted should strive to fix medically (Tregaskis, 2004).

The social model “of disability sees the problem as located within society. Rather than attempting to fix the person with the disability, the focus should be on the removal or amelioration of social and environmental barriers to full social, physical, career, and religious participation” (Quinn, 1998, p. xx). The social model focuses on the disability as originating outside the body, that it is the environmental limitations and organization of society that make a person disabled. Through adjusting the lens of the origin of disability, the social model places the duty of action into society’s hands, rather than the individual’s (Tregaskis, 2004). As all of us, to some extent, have had some kind of a disabling condition at some point in our lives.

The World Health Organization now incorporates both the medical and social model into their definition, defining disabilities as:

... an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives” (World Health, 2001).

The incorporation of the social aspects of disability into their definition indicates a move towards a compromise between the social and biological models.

The biological impairments of the children included in this ethnography are undeniable. None of the nine children visiting Ramón during my stay were able to walk. The children that were present during my stay were had similar abilities to most of the children Ramón sees, as he takes many extreme cases of physical impairment. Most of the children were unable to talk. These children are considered, by most standards, children with severe disabilities.

Biological or Physical Impairment. Impairment is defined as “the functional limitation within the individual caused by physical, mental, or sensory impairment” (Tregaskis, 2004, p. 10). Impairment in terms of bodily functioning is real. Whether born with impairment or acquired through an injury or illness, there are real biological impairments that cause the brain and body to behave in ways that are outside “normal” function. The children that visit Ramón vary in impairment, but are quite homogeneous in severity (how much their function is affected). The conditions of the children in this ethnography range from cerebral palsy to the after effects of meningitis.

Cerebral Palsy is the most common biological impairment among Ramón’s clients. While there is a range in severity among children with Cerebral Palsy, all of the children who see Ramón are on the severe end of the spectrum. Cerebral Palsy is defined by encyclopedia Britannica as:

...a group of neurological disorders characterized by paralysis resulting from abnormal development of or damage to the brain either before birth

or during the first years of life. There are four types of cerebral palsy: spastic, athetoid, ataxic, and mixed. (Encyclopedia Britannica, 2009).

While few of the parents in this study specify the type of cerebral palsy (one specified ataxic and spastic), all of the involved children are unable to walk.

Biological impairments are translated into disability in today's society through praise placed on strength, youth, mobility, and independence. While biological impairments are sometimes important to understand for practical purposes (how best to help those individual), they are also overemphasized as a mark of being different. While helping those with biological impairments, society often tries to make them "normal," which is not necessarily the best way of "helping" (Smart, 2001). The desire to "fix" biological impairments so as to normalize the children in mainstream society is different than acknowledging those who have extra needs and meeting those needs. The medical model places emphasis on fixing biological impairments as a way to rid the individual and society of disability.

Biological impairment originates within the body; disability is constructed in how society treats these impairments. Tregaskis cites Barnes' (1991) definition of disability, as "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (2004, p. 10). How these biological impairments affect day-to-day living is different in two social settings: in the client's home country and in Ramón's small community in Chile. In the first, these children are disabled, while in the later, they are normal (with biological impairments).

How do these impairments determine how their (the children and their families) daily lives are lived? What does it mean to be disabled in one context and what are the implications of being disabled in that society?

In the states, or the country of origin of these children, they are children with disabilities. In Chile, they are children who are attempting to have greater mobility amongst many other children with the same or similar goals. For these children, though they are there to walk to become more “normal,” while being a member of this isolated community, in essence are *the normal*. Goffman speaks of “the normals” as “we and those who do not depart negatively from the particular expectations at issue” (Goffman, 1963, p. 5). The notion of disability rests on the notion that there is a normal and there are outliers. Often “normal” is defined as absence of disability or deviance (Smart, 2001). Who is normal and who decides? If those that are normal are the majority, then in Ramón’s isolated community, wouldn’t the majority of children there be normal, even if those children were unable to walk and talk?

Normality is a social construction; normal is defined and supported through social action. The majority is considered to be “normal” and the minorities are considered to be disabled. Higgings (1992) states:

We have deliberately, often painstakingly, constructed our world in ways that “accommodate” those not known as “handicapped.” Often without reflection we have done so, too. For example, when we build stairs, we fit their height to many (but not all) people’s capacity to climb them. Of course, until just recently we have built stairs where ramps would have worked just as well. We run our “regular” schools so that the majority of children can at least survive within them, if not thrive... We “accommodate” non-disabled people in all realms of living.

(pp. 44-45)

The above quote is indicative of how those with impairments are treated on a day-to-day basis, and this ethnography speaks to how that might be different. The everyday lives of “normal” children in the Western World are characterized by school, homework, after-school activities (sports, music, recreation groups), and spending time with friends. Parents strive to enrich the lives of their children, to offer them opportunities. Carrying on with their lives without the need for assistance in walking or talking makes these children “normal,” at least to the general public.

What are the implications of being disabled? What are the social meanings of disability? Physical and social barriers are inherent to having a disability as these are qualifications of having a disability, other than these barriers there is also categorization (as disabled, or worse) and labeling. While everyone disabled or not deals with categorization and labeling, those with disability deal with judgments and stereotypes daily. Society has bought into the notion that it is acceptable to exclude a population from activities because they are “disabled” (Tregaskis, 2004).

Researchers have used the social construction of disability argument to look at a number of different “disabilities”. In addition to Groce’s study of a deaf community, Molloy & Vasil use the social construction of disability framework to look at Asperger’s syndrome. They question whether Asperger syndrome is “an actual impairment as opposed to a neurological difference” (2002). This use of the social construction argument posits that “actual impairments” are different than neurological differences in that impairments are the actual limitations of the

body, whereas disability is associated with how society views and treats these impairments (Molloy & Vasil, 2002). An example illustrating the difference between the two is that “Impairments, such as the inability to hear, exist in the world, but deafness, as a disability, is socially constructed ” (Molloy & Vasil, 2002, p. 663). Exclusion from activities because of an individual’s inability to hear creates disability, just as a person unable to walk is not disabled until presented with a staircase or the like.

How biological impairments are translated by society, either into disability or normality, depends on the society and community in which those with impairments are living in (and where they are socialized). Within the context of this thesis, I argue that the children with biological impairments are disabled at home (in the US, Canada, Argentina, and Israel) and in this isolated community in Chile they are “normal” children with biological impairments.

A day in the life of...

What is it like to be disabled? To be disabled means to be distanced from the non-disabled. The interactions between people with physical disabilities and those without are often distanced and shortened by the able-bodied participant (Albrecht, 1976). It also may involve being falsely stereotyped and to be the subject of ridicule or “the stare.” The stare refers to people looking at the physically disabled with pity, often assuming that there is something else “wrong” with the individual. “The stare” happens daily for children with disabilities and was evident in my travels (to see Ramón) with Mae. In the airport for example when security checks the wheelchair the attendant would only speak to her mother or

me. When we informed them that Mae can understand and respond to them, they spoke loudly as if she also had a hearing impairment. On yet another occasion, the security attendant just walked up and pushed Mae off beyond the security wall without saying a word to her, treating her as a non-person. Mae, Kate, and I have conversations on occasion regarding how to respond when people just stare open mouthed at you (We never really come to a consensus though it always makes us feel uncomfortable or unwelcome). Beyond the social implications of having a physical impairment, there are many practical implications for individuals with disabilities while they face the challenges of activities of daily life much like those without impairments.

When asked what a typical day is like at home for these families, many of the parents were surprised by the question, responding, "What do you mean? It's a pretty normal day." The parents talked about getting the kids up and taking them to school if they are old enough, taking them to therapy or having the therapist over, doing homework or exercises, then the rush to eat dinner and get cleaned up before bed. If I had removed the therapy from that normal day, it might not be apparent that these children have severe developmental disabilities. Most of the mothers stay at home to take care of their child or children (8 of 9). These parents are participating in daily rituals that are typical of other parents; they meet friends for dinner and they take their children to birthday parties and/or to the park.

The parents of these children say that their lives are pretty much like those of typically developing children, only different based on the amount of time and

energy being put into that (daily life) regularity. The parents of these children with disabilities work every day to make these children's lives do-able. Most parents of typically developing children do not have such worries on a daily basis. The amount of energy involved for both parents and children with disabilities to fit into after-school activities and to schedule assistance and accessibility is far beyond the energy and planning necessary for typically developing children (Hansen & Philo, 2007). For instance, when signing up a child for an after-school activity, the parents of a child with severe physical impairments often have to consider whether or not the building and activity is wheelchair accessible.

Hansen and Philo refer to this extra energy by those with disabilities (or their parents) as: "embodied 'art' of managing the time, space and speed realities of 'doing' daily living demands more recognition that it usually receives" (Hansen & Philo, 2007, p. 497). For parents of children with biological impairments, the energy involved in getting up, getting ready for the day, simply getting the child out of bed, cleaned up, fed, dressed, massaged, and out the door is vastly more demanding than for children without biological impairments. One mother, Rita, when asked about day-to-day details, discussed getting to take a nap at the office:

"I have to rush rush rush feed him before he close his eyes because he is so tired by the time I finish feeding him I put him to sleep I use the other office I put an exercise mat, I have his clothes here and everything, I put his pajamas on and he sleeps usually for two hours, when he wakes up, usually he sleeps well... if he doesn't it screws the whole days schedule."

For parents with typically developing children, after-school activities fulfill two functions: to keep the child while the parent is at work or busy with other

things and/or to socialize and enrich the child. For children with impairments, often activities require more energy from the parent and closer supervision, while the effort to enrich remains the single, salient goal. For children with impairments, parents need to attend activities, hire or recruit someone to go with their child, or make arrangements with the after-school group to ensure that all of the child's needs are met. In a conversation with Janet about what mainstream school in the US was like for her daughter, she indicated that often there was resistance or questioning about why Janet and Ella did things the way they did. Ella drinks milk while lying down as a snack and Janet retold a story of how the people in school were uncomfortable feeding her in that way. Because many of these children are reliant on an adult for all activities of daily living, experiences like uncertainty over how to feed are cause for stress among parents of these children. Even when these goals are accomplished, there is often a constant worry on behalf of the parent regarding the wellbeing of their children in the hands of other caretakers (e.g. are they being treated well, is the caretaker able to understand the way the child communicates, etc.).

While many of the activities that these families partake in are similar to those of "typically developing children," there is considerably more effort on both a pragmatic level and on a more general level of support systems. When visiting Ramón, both the pragmatic and the supports are shifted in perhaps a more manageable way for parents. The Jewish school in Chile (where two of the children seeing Ramón are enrolled), which is just a short drive from Ramón's office, is very welcoming to children who function differently. One of the mothers,

Lucy, went and checked out the school and found the school to be a great fit for Daisy and her other children. Lucy then spread the word about the accommodating school staff to children with impairments, resulting in another mother enrolling her daughter. Janet mentioned that finding this school was a relief to her and that the school seems not just accommodating but actually “happy to have Ella there.”

When families visit Ramón, the pragmatic details of day-to-day living are different than at home. The things that many “non-disabled” individuals take for granted are daily challenges for individuals who do not move and/or communicate in the same ways as most. Practical issues like being able to physically access a space or being able to communicate ones needs, thoughts, and opinions to others are those that are often taken for granted by those without disabilities. To illustrate a few ways in which practical issues are handled different, we look at the physical access to buildings and also at flexible communication.

Mobility and Wheelchair access. What does it mean to have access to a physical or social space? To be denied access to a building or function because of a disability has been justified in the past, but what does it mean that we build buildings the way we do? Literature within both geography and disabilities studies have addressed wheelchair access and how that is an indicator of societies’ acceptance and inclusion of those with physical impairments (Marks, 1999; Meyers, Anderson, Miller, Shipp, & Hoenig, 2002).

Environments physically exclude disabled people and ... the degree to which architecture and design are oriented towards the comfort and

respect of all those who wish to navigate the built environment. Design aesthetics reflect certain idealized assumptions about the inhabitants and users of the build environment” (Marks, 1999, p. 82).

In addition to the social implications of physically barring access, social roles are also limited because of physical barriers. Albrecht argues that through lack of “physical mobility”, individuals are prevented from engaging in important “social roles in life” (1976, p. 27).

Buildings and most other places are wheelchair accessible in Ramón’s isolated community in Chile. This is due in part to the fact that Ramón’s community is small and isolated, but also that he has chosen the location of his office with wheelchair bound children in mind. Ramón’s office is situated in such a way that everything is wheelchair accessible, the children in chairs are able to go to all the same places that those who can walk access.

Smart states: “Respect is better than pity” (Smart, 2001). In this setting in Chile, it appears that these children are looked at with respect rather than pity and offered prospects to access both physical and social opportunities. Wheelchair bound children in Ramón’s community are not looked at with pity, but instead with care and respect. Often in mainstream society, in which “the normal” are those who move independently and are able to speak, people in wheelchairs are treated as if there must be other things impaired about them (Russell, 1998). In Ramón’s community, children and adults alike have a greater comfort level with individuals who function outside of the “norm” and look beyond the wheelchair or appearance and ask about the child, inquire about what the child likes to do and how they do it. There are no assumptions that the “disability”

is all there is to the child in Ramón's community, and individuals are able to explore and appreciate other aspects about that child. The initial discomfort that many people feel around wheelchairs, as is evident in the earlier examples of Mae and I at the airport, does not exist in Chile.

Communication and language. While there is an emphasis on mobility in order to participate as an independent person in society, communication and language have perhaps even larger implications. Language has been said to be "the most important sign system of human society" (Berger & Luckmann, 1967, p. 37); for children who are unable to verbally communicate or even use sign language, the implication is colossal. In the US and all modern societies, there are "standards of proper speech" which are acceptable and necessary for living in society (Berger & Luckmann, 1967). Berger and Luckmann cite "improper" language as being an inside language that one might use with their child which is not acceptable for use outside of the isolated context of conversing with a young child in one's own home (1967). The limitations of our modern language system (necessitating the spoken word in mainstream society) often leave many of the children in Ramón's community unable to fully participate in this important sign system in day-to-day interactions. An example of participation is through conversation, being offered opportunities to engage with others and being able to overcome stereotypes. One of the ways in which we use language is to challenge typifications, or generalizations about a person based on certain social characteristics, Berger and Luckmann speak of the 'Englishman' while you have expectations as to what this person will be like and when you meet them in

society their actions, demeanor, and most importantly what they say challenges or confirms these typifications. If in mainstream society, a person is excluded from the most important sign system to communicate with those they come into face to face interaction with, they are seriously limited in their ability to challenge these typifications.

An example of access to communication and participation is presented one day in Ramón's office when two mothers and their children were in the waiting room. One mother was waiting for her daughter to finish therapy, and Kate, Mae, and I were waiting to go into therapy. Lucy began a conversation with Mae about what types of things Mae liked. The mother spoke of how her daughter likes princesses, and asked Mae if she did as well. Mae was given the opportunity to respond and continue the conversation using her unique form of communication using a combination of eye gaze and body language (with interpreting by myself and her mother). Mae indicated that she didn't really like princesses that she was too old for that. This example may not seem all that rare unless contrasted with mainstream society. Individuals (who are not very close to Mae) rarely give her an opportunity to respond nor really know how to give her the opportunity, assuming she cannot because of her position in a wheelchair and inability to speak verbally. Instead of allowing her room to communicate, people typically speak only to the adult with her, or make statements to her (e.g.: "Oh you must love Disney!").

The children present in Ramón's office all communicate in different ways; there is no one form of communication that is common among all the children.

Some communicate with their hands (sign language), others communicate with their eyes (gaze or blinking), some with limited verbal skills, some with body movements (a shrug of the shoulders or a leg movement), and yet some combine all of the above into a mixed communication method. In this community, it is expected that a child will communicate using multiple forms and/or that they might rely on another person for help with communication.

One day while in Ramón's office, I sat in on a session with Maybe, the Venezuelan speech therapist. She speaks only Spanish and was working with Mae (who has grown up in an English speaking environment), who primarily uses her eyes and body to communicate. During that session, a colleague of mine also sat in on the speech session. She is an English teacher in Chile. While Maybe spoke in Spanish, Allie translated into English, and I told them both what Mae was saying with her eyes and body. During the session, Maybe would ask Mae to say certain words and sounds, in some cases she relied on Allie to tell her what the words were in English. In other cases, Maybe would ask Mae what she was doing after the session and Mae would look behind her, indicating that she was going outside until her next session. Allie would translate to Mae what Maybe was asking, and I in turn would interpret Mae's answer. The session was anything but frustrating, it was enlightening as to how many ways there are to express an idea, and with patience and in the right environment it can be very rewarding.

During my first stay in Chile, I had many conversations with one mother about the ways in which her daughter communicates. Janet's daughter is also

unable to communicate verbally and yet there are many opportunities for her to communicate with other children, parents, myself, and Ramón. Throughout my interactions with Janet and her daughter Ella, Janet explained to me the ways in which Ella communicated. During conversation Janet would often point out to me how Ella was contributing and over time I was able to notice her participation and engage with her. During our lengthy interview, Janet explains: "Because she wants to be a part of the conversation ... she holds her eyes closed [for a period of time] or a really long opening." She went on to describe how a new incorporation into her communication evolved: "she was trying to capture his [Ramón's] attention...now she can say yeah with her voice. That one came out like a whisper but it's still a word." Flexibility in communication within Ramón's community allows these children opportunities to challenge common first impressions of children in wheelchairs. Asking children and parents how they best communicate is a way that life in Ramón's community is different than life at home.

Normalizing: Ramón's community in Chile. One of the ways that life differs for these children while in Chile is that their whole worlds revolve around therapy to develop their walking abilities. There are no misconceptions about what the priorities are for these children. For example, I asked: What is a typical day like here and how is it different than being home? One mother's response was:

"It is very different when I am at home because over here, I am here for therapy and I have nothing else in my mind other than therapy. Which helps a lot because if I was in Toronto with Simona I wouldn't be able to do this because you have the home, other appointments; you have people, other obligation, but here I am here for therapy and I am not here for people, I am saving money, I am ALL here for therapy..."

In Chile, the expected rituals are different from those at “home.” These parents have stated in no uncertain terms that their priorities are with Ramón and their child’s independent mobility. Much like the day in the states, the parents say that in Chile they also have a typical day, except that it is centered on therapy and their child/children. Some mothers expressed relief from the pressures they experience in the United States. One mother, Rita, felt that in Chile she only had to do what she wanted to do, she didn’t need to meet people socially if she didn’t feel like it, and she didn’t need to cook dinner for her husband. Her stay in Chile was liberating of the typical daily rituals expected of this mother. Others felt liberated not to have to enroll their child in school right away and face the trial of having a child with severe impairments in a mainstream school.

Ramón’s community in Chile provides an alternative context for these families within which the main goal is for their children to walk. In their quest for that goal they have found a place in which their children are *normal*. The normalizing of disability within Ramón’s isolated community was not a conscious reason for any of the families to come to Chile. In fact, CME therapy is within the medical model framework, with the goals of helping these children to walk, or get “well.” Some families seem to enjoy that their child is normalized, that they are able to speak freely about what their child needs, have conversations about alternative or assistive communication devices and special order shoes. One day in the waiting room, Lucy was expressing concern about her daughter, Daisy, communicating in school. Her daughter’s vocal skills are limited and often used in

the form of a giggle or scream. Kate, Mae's mom, mentioned that she had the same fears when her daughter started school (and sadly they never went away), but one thing that made communication easier was a small touch screen computer called a "Dyanvox." The conversation continued on how and when it is used and what other adaptive equipment might be of assistance for her daughter. This interaction might be compared to typically developing children's mothers discussing ordinary school supplies or even simply where to buy sports equipment or clothing.

Another example of positive normalizing of disability is through mentoring of the older children with the younger children. Daisy, who is six, looks up to another child (Mae), as a role model or "cool older kid." Daisy looks to Mae to see how older children act. During one of Mae's therapy session, Daisy's mother asked if they could sit in on the session so that Daisy could see how Mae walks with Ramón, to see where she might be someday in terms of mobility. The positive outcomes of normalization for these children are unintended consequences of visiting Ramón, making the trips much easier in some sense for the families (and sometimes making leaving harder).

On yet other occasions, mothers (and children) appear less thrilled about their child being normalized in this way, as they came to this office Chile with hopes that their child would walk, to "be normal" out there in "the real world." After being fitted and receiving a new wheelchair, Lucy's daughter was driving herself around the office. Lucy was telling us how Daisy was not happy to be in a "big girl wheelchair." Daisy interrupted to tell us that the chair was "stupid" and

her mother prompted her to go on to say that “it is okay because it is not forever.” Most parents, a great deal of the time, are somewhere in between; parents feel both good about the situation (their child is the norm_ and yet at other times feel as if they wish they didn’t have to have anything to do with this community. A compromise between enjoying the community and wanting out seems to be prevalent in discussing Ramón’s successes.

One of Ramón’s most celebrated success stories is of a child from Toronto, ‘Teya,’ who was diagnosed with Cerebellar hypoplasia.² Her doctors’ and therapists’ consensus were that she would never walk and that her mother should seek a wheelchair that she would feel comfortable in. ‘Teya’ is now walking completely independently. Her mother and ‘The Foundation For The Deaf’ have created a website, fund (‘The Teya Fund’), and video to publicize her success and to raise money and awareness for other children in similar positions. It is common for parents to discuss Teya’s story with their children and amongst themselves. One day in the waiting room, one mother, Kate, commented that her family has watched the video so many times that her second to oldest daughter (five years old) had the words memorized. They had plans to meet Teya while visiting Ramón in Toronto, but they were unable to make the meeting happen.

² “Cerebellar hypoplasia is a neurological condition in which the cerebellum is smaller than usual or not completely developed. Cerebellar hypoplasia is a feature of a number of congenital (present at birth) malformation syndromes, such as Walker-Warburg syndrome. It is also associated with several inherited metabolic disorders, such as Williams syndrome, and some of the neurodegenerative disorders that begin in early childhood, such as ataxia telangiectasia. In an infant or young child, symptoms of a disorder that features cerebellar hypoplasia might include floppy muscle tone, developmental or speech delay, problems with walking and balance, seizures, mental retardation, and involuntary side to side movements of the eyes.”
http://www.ninds.nih.gov/disorders/cerebellar_hypoplasia/cerebellar_hypoplasia.htm

Rita remarked about Teya:

“... I mean the girl she doesn't have part of her brain. She doesn't have it... she was born without it... she is a miracle. She did it, she is walking, she has her independence. Every time I feel bad or I feel this might not happen and I know that it will happen as long as I continue with Ramón. But for me Teya's video is also very important to give me... you know there's those sad days. I go and watch the video and I see Teya's video and it puts me back on to my normal.”

This story highlights the importance of success stories for Ramón's clients in keeping them positive. It also highlights that while they might enjoy the positive aspects of being in this normalized community, they are also eagerly awaiting the day when they will “graduate” from this community, a day when instead they will be a success story to be told by Ramón's future clients and families. During one of Daisy's therapy sessions, Ramón and Daisy were working on an exercise that was very challenging for Daisy. Lucy, her mother, began talking about Teya and how she had done this with Ramón on her video. She engaged her daughter in a conversation about how Teya had struggled with it and that she needed to keep trying.

Social Supports: Creating and recreating. The sharing of experiences and stories highlights the next way in which disability is normalized and also the importance of support and sharing experiences with one another. Social support is “the perception or experience that one is loved and cared for, esteemed and valued, and part of a social network of mutual assistance and obligations (Taylor et al., 2004). Social support is an important aspect of adaptation and coping for

families with disabilities (Horton & Wallander, 2001; Shin, 2002). Research on social supports has shown that reducing stress helps parents (mostly mothers) cope (Taylor et al., 2004). Shin (2002) found that for American mothers of children with mental retardation, the largest form of support is from the child's siblings (18%) and then from their husbands (17%). In terms of formal support, the area where American mothers received the most support was from the school, namely special education teachers (Shin, 2002).

In view of the current study, I expected at first that these families would be removed from their social support systems and in a state of isolation during their stay in Chile. Social support is very important for parents of children with disabilities as is discussed in Part III on gendered parenting. While in some of the cases there were parents who mentioned missing the other parent or missing the childcare/assistance they receive at home, surprisingly, the parents expressed that being in Chile was an environment in which there was a great deal of social support. For example, one mother states: "...and with Claudia other than the physical help, the emotional help we share in talking, her life experience and my life experience. So it is not just like some secretary there, we are like family and friends and we share in everything day by day." Claudia and Ramón set up transportation to and from the airport and they supply a cell phone for the family for the duration of their stay to make the transition into Chile a bit easier on the families. Claudia can often be found on the phone for one of the mothers regarding a doctor's appointment or even with a Laundromat to ask them (in Spanish) if a family's laundry is ready for pick up.

This support comes both from Ramón and his organization and from the other families present. When one of the children was sick, his mother, Rita, was having a difficult time accessing a doctor and also completing daily tasks- like grocery shopping. Two of the other mothers present brought her food or had their cooking helpers make enough for both families. During my interview with Rita, the phone rang and it was Janet indicating that she had lunch waiting for her. She offered to bring it down for her daughter's later appointment. I ended up going upstairs to Janet's apartment and getting the lunch for Rita and her son so she could remain with him and hear him if he awoke from his nap in the extra room in Ramón's office. Social support also arose in the form of giving one another a break and having "fun" time. Upon my arrival in March, a few of the mothers were talking about how they had gotten together a few nights before for dinner and dancing with a therapist who was visiting Ramón from Canada. Janet informed me that it had become a bit of tradition to go to Lucy's on Saturdays. Three of the families got together at Lucy's house and the children swam and the mothers had an opportunity to relax together watching the kids play.

In addition to down time, parents are able to ask one another for advice and about their experiences in this community to prepare them for what to expect in much in the same way a new parent may ask advice of a seasoned mother. One day when Lucy was feeling quite frustrated about Daisy's attitude during therapy (she was arguing with Ramón and calling him names) she asked me what Mae was like at her age and if she acted out like Daisy (I was unable to answer this). While Lucy has older children, it was a unique opportunity for her to

be able to ask about a child who is in a similar situation to her daughter namely they are both reliant on adults and wheelchairs and going through intensive therapy. This community provides opportunities for parents to support one another and share in experiences of raising children who function outside of the norm.

A third form of support that was helpful and salient from home to Chile was religion. Many of the parents of children who see Ramón in Chile are Jewish, and they find additional support from the Jewish community in Chile. The community provides a certain comfort level, a familiar setting in an otherwise mostly foreign environment (the rest of Chile, for example language and cultural barriers). Rita lived within the Muslim community for a while when she arrived in Chile and found comfort in common rituals and holidays. While the religious communities offered comfort, familiarity, and a place to celebrate beliefs, those beliefs were also celebrated and shared within Ramón's community. For one Jewish holiday, Lucy brought in food for all the families and told the children what the holiday was about and Daisy was dressed up as snow white (as a part of the holiday tradition the children got to dress up). Lucy told me that she found it comforting to have the Jewish community present as it gave her a way to relate, though they do not share language or national culture, they share religious beliefs and rituals. She went on to say that while religion was important, she also had so much more in common with the people in Ramón's community.

Therapy decisions: Dropping "normal lives" for Ramón. Why? Out of desperation? The parents that are in this ethnography have rejected the notion of

how to live daily (for varying periods of time) and replaced it with a new idea of how they should live their daily lives. They have “picked up their lives” in exchange for a life that is centered on Ramón and maximizing their child’s mobility. Over and over again these parents have been confronted with the question: “So you’re just going to pick up your life and move to Chile... for a therapist?” Rita, in discussing her decision to not return to school immediately and instead to move to Chile, states: “Then before I came here, my friend from there [Canada], said: ‘are you crazy you are going to a country you don’t know, a language you don’t speak you have no idea what is going to happen.’” Rita’s husband, while being uninvolved in his son’s life was resistant to his wife and son going to Chile for treatment. Rita attributed this to his lack of knowledge on therapy and his son’s needs. She said she started by just telling him she would go for one month, then two months, then six months. She stated: “...now he knows it the right thing it’s the best thing for Yussuf, he saw changes and it’s easier for me to convince him to extend the period now.” Kate discussed how people approached her about her decision to come to Chile and unlike in Rita’s situation, the concern was over money and the expenses of the trip. She indicated that some people thought she was “nuts for spending that kind of money on a therapist.”

Often times when parents tell friends, families, and strangers that they travel abroad for treatment, there is a sentiment that they are “desperate.” It is not uncommon to hear: “Wow, they must be desperate if they are flying to Chile for treatment, what’s wrong with therapists in New York?” Is it desperation that

drives these parents to come to Chile? What is desperation? Merriam-Webster dictionary defines desperation as “1. loss of hope and surrender to despair; 2. a state of hopelessness leading to rashness” (Merriam-Webster, 2009). Accepting that definition of desperation, these families are not traveling to Chile out of desperation. In fact, none of the parents made “rash” decisions to move to Chile, all of the parents mentioned researched both online and through speaking with other families about their experiences with therapy. One of the mothers, Janet, had been bringing her daughter to Ramón for 10 years at the time of my visit. She indicated no signs of loss of hope or rashness, nor any indication that she was going to move on to another therapist out of desperation. Many of the families (eight in total) had tried other therapies prior to Ramón; however, none of the parents mentioned “loss of hope.” In fact, all the parents felt that they had an assortment of other options for therapy, but none of them were as good as Ramón. Viewing Ramón as the best option, not necessarily the “last” option is crucial for understanding the motivations for families moving to Chile to receive Ramón’s therapy. Miriam’s father discussed at length with me his plans for seeing Ramón. He talked rationally about how he had moved here to give it a try and were still determining how long they should stay (he asked me at length how long most parents stay, if I have found a certain period of time to be the best amount for maximum progress). The interactions among parents and conversations about decisions to come to Chile never indicated in any way a “rash” decision or hopelessness.

Prussing et al. (2005) examined the duality of “desperation” and “disability rights” in the use of complimentary/alternative medicine (CAM). Their research addresses the critical notion that parents of children with developmental disabilities look to complementary and alternative medicine out of sheer desperation when faced with no other promising medical options (Prussing, Sobo, Walker, & Kurtin, 2005). They found that, in fact, seeking out CAM it had more to do with human rights and the parents wanting the very best for their children than with ‘desperation’ (Prussing et al., 2005). All but one of the families had tried therapies other than CME and all of them acknowledged that there were other options for their child, they just were not as good. The only family that had received only (exclusively) CME is Rita and her son, who started receiving CME at 4 months of age and his mother proceeded to find higher-level therapists, eventually finding Ramón and moving here to work with him. The fact that all of these families seek many other options for therapy indicates that in fact desperation is far from the motive behind seeking out Ramón.

One father from Argentina, Jacob, mentioned that just prior to coming to see Ramón for the first time, they needed to make a decision between two therapies and they choose Ramón’s CME therapy. Jacob’s family lives in a Jewish community in Argentina where there are many children with “issues,” the father commented that his son needed Ramón to help him walk and that the other children in the community were receiving standard NDT therapy. Jacob’s family flies up to see Ramón for a few days as often as possible and his son engages in CME at home in Argentina. Within this community, the decisions of

parents are also normalized in that they do not have to defend to one another that their main goals are maximal independent mobility for their children. This community provides a relief for parents in a context of competing options and social assumptions, where they can just be accepted and unquestioned for once. Therefore in addition to inadvertently normalizing disability, this community also normalizes the decisions of the parents.

Conclusion: Social Construction

Ramón's community normalizes disability. The biological impairments that these children have are accepted and translated into normality rather than into disability. Using the social construction framework, I have examined the daily lives of these children and their families while visiting Ramón, including the day-to-day events and barriers and incorporate literature on the daily barriers faced by children (in mainstream society) with disabilities. Through the discussion of normality and disability, and important aspects of everyday life that are critically different at home and when in Ramón's community that contribute to the normalizing of disability, Ramón's community. Through minimizing the physical and social barriers that these children and families face daily that bar access to full participation in society, these children are able to fully participate in the daily reality of this isolated community.

Hansen and Philo recommend "shifting the emphasis from (aiding disabled people in) *doing things 'normally'* to (underlining for all of 'us') simply the *normality of doing things differently*" (2007, p. 493). This ethnography moves

toward a deeper understanding of how disability is constructed in society and begs for a deeper look at the current ways in which the “disabled” are treated in society and ways in which it could be differently viewed. As disability is a socially made label and reality, when then can it not be normal in society to do things differently? The next section of this thesis will address how Ramón is able to create this environment and what the relationship between Ramón and his clients looks like.

PART III-THE HEALER/PATIENT RELATIONSHIP AND THE CHARISMATIC HEALER

Ramón, as both the founder of Cuevas Medek Exercises (CME) and as a physical therapist, is what Sociologists might consider a charismatic healer. He instills faith in his patients that he is the right therapist for their needs and has successfully created an international physical therapy organization with himself as 'head.' I consider Ramón to be a charismatic healer with a unique relationship with his clients reminiscent of a doctor-patient relationship of the past. Part III of this thesis is split into two main sections: the healer-patient relationship as explored through the doctor-patient relationship including a brief history, the characteristics of the relationship in the past and at present, the reasons for the patients or their families seeking out Ramón, gendered care giving, and lastly a discussion of whether or not Ramón's relationship with his clients fits with yet another medical phenomenon or model. The second half will deal with Ramón as a Charismatic healer relying on Weber's notion of Charisma, providing an evaluation as to whether Ramón fits Weber's notion of a charismatic healer, the qualities and characteristics of a charismatic healer and their relationship to their clients, and lastly the community that is formed by Ramón and these families.

The Physician (Healer)-Patient Relationship

I will begin the exploration of Ramón as a healer through examining how the doctor-patient relationship framework might apply to Ramón and his clients. I turn to the doctor-patient relationship to better understand Ramón's interactions with his clients for a few reasons: first, there is a relative paucity with respect to research on the physical therapist-client relationship. Secondly, the circumstances surrounding the interactions between Ramón and his clients (i.e. being in Chile, seeing them three times a day) create much more frequent and intense interactions than of most physical therapists and their clients. Thirdly, through his charisma, Ramón is seen as much as a "healer" as he is a therapist, making the doctor-patient framework one that is applicable for this thesis. Starting with a brief history of the doctor-patient relationship and its evolution, I will then look at the asymmetrical power distribution within the doctor patient relationship, address paternalism within the doctor-patient relationship of the past and within Ramón's relations with clients today, and finally end with how Ramón does or does not fit into the doctor-patient association of today. I will then offer alternate frameworks/ways of viewing Ramón's relationships with his clients and their families, namely within the context of complementary and alternative medicine, the faith-healing tradition, and lastly medical tourism.

The relationship between a physician and patient has undeniably changed throughout history (Potter & McKinlay, 2005; Starr, 1982). Paul Starr (1982)

details the evolution of this relationship. A relationship that saw limited power of the physician at its start, then transformed into one in which the physician held a great deal more power and medical knowledge, offering that physicians “serve as intermediaries between science and private experience, interpreting personal trouble in the abstract language of scientific knowledge” (Starr, 1982, p. 4). Today, the relationship between a doctor and patient is characterized more as an encounter, with greater relational distance (Potter & McKinlay, 2005).

I find that a variety of the doctor- patient relationship exists with Ramón (charismatic therapist) and his clients (the children and their parents). The doctor-patient relationship in the mid 20th century was characterized as paternalistic, with the doctor acting as a father or advisor for the best welfare of the patient (Potter & McKinlay, 2005). This relationship, common in the mid 20th century, has since been replaced with a more complex relationship involving multiple actors (Potter & McKinlay, 2005). These actors who have entered the relationship include: insurance companies (May, 2007), pharmaceutical companies, and even advancing technology (Pearce, Trumble, Arnold, Dwan, & Phillips, 2008). The current relationship between doctors and patients has been characterized with “superficiality and focused on here and now” (Potter & McKinlay, 2005, p. 476). Today physicians and healers are charged with treating parts of the person rather than the whole person, sometimes with more of a focus on productivity rather than on caring for the patient (Potter & McKinlay, 2005).

The relationship between Ramón and his clients more closely resembles the doctor-patient relationship prevalent in the mid 20th century. The relationship

between Ramón and his clients is not convoluted with insurance companies or any other third party for that matter. Ramón is not associated with any parent companies or corporations, nor does he accept payment through an insurance company. The parents of the child receiving therapy are expected to pay Ramón at the end of the sessions or every few weeks with cash or check. Ramón deals directly with payment usually involving a short conversation about his rate and confirming the number of sessions the child had attended; there is no third party or middle-man. When asked about this, Ramón responded that he is a private therapist, citing that he saw no need to be involved with insurance companies. All the patients' families in this ethnography felt that the price of therapy is both fair and worthwhile.

Often therapists that have been formally trained under Ramón will work for agencies or organizations that accept insurance. Some families that are in Chile seeing Ramón have therapists trained under him at home (and often covered under their insurance plans). Sometimes that is how families of patients are introduced to the option of going to Chile. One mother, Rita, left her therapists in Canada, one of whom was covered under the universal health care and another of whom was not (both CME therapists, level one and four respectively). Mae's sessions with her therapist at home (a CME level three) are partially covered through insurance and partially paid for out of pocket.

The simplicity of the relationship between Ramón and his clients is also similar to those of the past; while there are very few cases or times where the relationship was only between two people (Wilde, 2007), i.e. from the early days

of the rise of the physician, the family, the patient, and the physician were typically those involved (as is the case here with Ramón and his clients). This relationship is characteristic of the physician in a power position much like a parent-child relationship (Potter & McKinlay, 2005). The families seeing Ramón are very comfortable in his office and often give him health updates, such as how their child is sleeping and eating. These interchanges between Ramón and the parents, often mothers, are more reminiscent of a domestic relationship than a professional one. Due to the unique circumstances in which Ramón treats his clients, namely that they have often traveled from another continent specifically to see him, the relationship is necessarily different than in modern medical or physical therapy practices.

Relational power/Power inequality. Early relationships between a physician and patient were inherently unequal in terms of power relations (Bloom, 1963). The inequality within the power relationship has many sources, the main being the unequal levels of knowledge and expertise in medical issues (Freidson, 1970). The salience of this power is imprecise. Is a doctor more powerful in all aspects or just within the scope of his expertise as a healer? Parsons argues that his inequality is functionally specific and that those inequalities do not necessarily translate into other situations outside of the medical encounter (1975).

Applying this relation framework to Ramón and his clients raises the question of how power relations are manifested within these relationships. Starting with the most obvious, these families have moved “to the end of the

earth” for Ramón. One family from Israel, whose son, Matthew was seeing Ramón, discussed the challenges of finding childcare for their other children and trying to pack enough food for the whole trip into their suitcases. They said that the preparations were very difficult for the trip. In addition to the travel and leaving of typical daily lives behind, appointments and scheduling revolve around Ramón, illustrating another way in which Ramón in his position as healer maintains power over the patient and their parent. Daily routines revolving around Ramón often means that these families’ daily lives literally revolve around Ramón and that he has the ability to shift their plans spontaneously. The decision as to when a patient is seen is indicative of the asymmetrical relationship between Ramón and his clients.

Ramón typically sees his patients for 45 minute sessions ranging from twice to four times a day. The number and times of the sessions vary depending on how many clients are in town, where Ramón is (Chile, Canada, and Belgium), and the child’s capability. Often Ramón will change the time of a session, sometimes just a day in advance or even on that same day. One mother, Lucy, when talking about her day-to-day life, described how she balanced getting her other four children to school and got back in time for therapy, detailing how she drops two off at school, then another one gets picked up at noon, then back to therapy and so on. She then said, “Well, I guess this will all change next week [when another family arrives].”

Ramón has the sessions lined up back to back (one ends at 10am and another starts at 10am). One feature that a mother found this frustrating is the

lack of time for discussion in between sessions, therefore Kate felt that she was paying to talk with Ramón about Mae's next appointment and any other concerns she has. In addition, families often dealt with waiting past their appointment time and thus needing to make other arrangements for transportation or childcare for their other children. When Ramón gets started late, that means that the next appointment is running late, and so on.

These details illustrate how the patients (and parents) are dependent on Ramón's schedule for making their plans daily and that these can change often. The power of the physician to decide the time and place of the appointment is not often the case in mainstream medicine and physical therapy. Flexibility in scheduling (a continuing trend in modern mainstream medicine) and going to the doctors on "your own time" is a reflection of a lessening power inequality between the physician and patient. Seeking Ramón is both a reflection of the consumerism movement, the notion that you can shop for the best, and also a reflection of compromise for the "right" therapist (allowing the therapist to schedule your day). With increasing competition and corporatization, patients often expect to be accommodated at their convenience. This trend is evident in the rise of "telemedicine" and email consultations with physicians via email or the Internet (Akerkar & Bichile, 2004; Andreassen, Trondsen, Kummervold, Gammon, & Hjortdahl, 2006; Car & Sheikh, 2004).

Ramón's power appears not to be limited specifically to the consultations or visit, but instead to infiltrate the activities of daily life for his clients and their families. Unlike modern health care facilities, Ramón is the only physical

therapist who works in his office and out of his practice. Modern health care facilities rarely consist of just one physician or therapist, through corporatization often there are many physicians or therapists available (or at least present) at any one time. On one occasion, Ramón left work to find that his mother-in-law had passed away while he was at work. He had his daughter, Claudia, call and tell his clients (she initiated a phone tree type system, where one mother called us, and we in turn called another). At this point there was no information from Ramón as to how much time he would be taking in order to grieve. The parents were in a position of wondering how long he would be gone, how long they would be in Chile without therapy, and what they should do from there. One mother, Kate, contemplated moving up her departure (to the US) because of Ramón's absence, illustrating how, truly, he is the only reason for their being in Chile. Kate expressed feeling both sad for his loss and annoyed at the dependency she had on Ramón for therapy and her decision to be in Chile, expressing that if he was not available there was no reason to stay. She and I discussed how hard it was not knowing whether or not to stay or go, and also feeling guilty for even thinking of such things under the sad circumstances. Ramón only took off one day for the services and remained "on call" for his wife, "if she needs him" when resuming therapy the next day. While Ramón requires of his clients that they be available when he is ready to treat them, he also displays a commitment to his clients through respecting that they have traveled far to see him and that there are no (or very limited) other options in Chile for them. While these families display the extreme of choice in health care, in that they have sought it abroad,

independent of any insurance reimbursement, they have also limited their autonomy over their care because of the choice to go to Chile. Ramón is essentially the only therapist that these children have access to once in Chile.

Ramón's commitment and trustworthiness seem to be a fair trade off for this lack of control over daily scheduling. While reviewing the relationship between physician and patient, it might also be important to understand a bit about therapy options in the United States in the mid-20th century. One of the key factors of the doctor-patient relationship of the mid 20th century was the role of medical decision making (i.e. doctor, patient, family) and the position of the physician as a main source for patients of their medical options (Starr, 1982). Patients often had little or no choice over which local physician they saw as there was typically only one per town or community (Starr, 1982). Therapies (physical and occupational) in the mid 20th century were just starting to arise, as NDT (Neurodevelopmental Therapy) the most common physical therapy was established by 1970. Prior to the 1970s, it was common for a child with disabilities to become institutionalized, or placed in a home or institution for the purposes of receiving care from paid workers (Nisbet, 1992). Nisbet states:

...in the 1970's, upon the birth of a child with a disability, many parents were advised to place the child in an institution. Simple notions and false assumptions about quality of life, about families' capacities to care, and about solutions to emotional crises motivated well-meaning professionals and families toward this choice. Nurses and physicians would sympathetically suggest that the new parents "go home and try again" while "arrangements" were made for the baby. (Nisbet, 1992).

This quote from Nisbet (1992) illustrates how far the medical field has come in terms of children with disabilities, but also the importance of using the physician-

patient relationship for comparison as the history of therapies is just now emerging.

This is a key point of divergence between Ramón's patient base and patients in the mid 20th century: while Ramón holds much power over everyday scheduling of therapies, these patients are very well informed as to their therapy options. None of these parents believed that Ramón was the only option; instead they believed that he was the best option. These patients (and their families) have a great deal of information about CME and other therapies and how they work, and were convinced that Ramón was the very best option. Ramón has exercises available online that parents can do with their children to see if CME might be a good fit for them (to see if they have the body/brain response to take to the therapy). After choosing to use CME therapy with Ramón, there are no minimum time requirements, only amounts of time recommended by Ramón, which is typically 8 weeks at the start. The access to multiple options for health care and therapy is consistent with a growing trend in health care and society today (with modernization) towards examining alternative options (Wilde, 2007). While engaging in modern practices of seeking out health care options that are a better fit for the child, these families are simultaneously engaged in a physician-patient relationship that is reminiscent of the past.

Paternalism: Ramón as father figure

The early 20th century relationship between a doctor and patient was one characterized by paternalism (Potter & McKinlay, 2005); it was a relationship in

which patients and their families looked to the physician for unquestioned advice. Most of the parents that come to see Ramón for long periods of time are mothers (80% according to Ramón's calculations; 100% of mothers were present on my trips to Chile and 3 of 9 fathers were present). Being literally continents away from the actual father figure in many of these children's lives, it is "natural" in some cases for Ramón to act as the paternalistic figure. For example one mother, Rita, who moved from Canada to Chile for 6 months, remarked: "Ramón is also very nice and very helpful just like he is our father and we are all like a member of the family... When he needs to take charge of something he does, when I need someone to be there and make a decision he does and he does it well."

The office set up is very casual and often a place where people share stories and even snacks or meals. During a few of my interviews with parents the phone rang. When Claudia is out either for vacation or even on lunch, parents answer the phone. Twice when in therapy with Mae, Ramón has asked her mother, Kate, to take a phone call for him. Another example of this paternalism is domestic tasks that mothers sometimes perform while in the office. Often during therapy, many of the mothers (four that I have seen, as well as myself) will make Ramón tea during sessions. The playfulness between Ramón and mother's who have been in Chile for long period of time is reminiscent of a paternal relationship. During my interview with Rita, Ramón came out of a session to go on his lunch break. Rita and I both stopped talking when he entered the room. Ramón said hello and Rita remarked to him that she was saying very bad things

about him (in reality she was singing his praises). We all laughed and Ramón replied that as long it was true that was perfect, what he wants.

Many days spent in Ramón's office were a reminder of the closeness of his relationship with his clients and also how paternalistic in nature that relationship can be. A few examples include birthdays as well as typical days. On Mae's birthday Ramón had a gift (purchased by Claudia, his daughter) ready for Mae to unwrap upon her arrival at his office while everyone sang Happy Birthday. On a typical day in Chile, Mae and I entered Ramón's office for therapy and Daisy was at his desk watching cartoons. He reminded her that she could only stay for a few more minutes and then his attention moved to us, indicating that he was ready to begin therapy. Rita, a mother who has chosen to live in Chile for the six months a year that Ramón is there, comes 5 to 6 days a week to Ramón's office with food, a change of clothes for her son, and anything she might need for the day. During breaks from therapy she changes her son, feeds him, lays him down for a nap in the spare room, often turns down the air conditioning so that he can sleep better, and makes herself lunch using the refrigerator and microwave. This constitutes another way in which Ramón's accommodation of these families is above and beyond any therapy needs, and is indicative of his paternal nature towards them.

Physicians and therapists throughout history have been known on occasion to withhold medical information or medical opinions on outcomes or prognosis because it was thought that it was better for the patient not to know (Steinhart, 2002). Doctors often took on the position of protection, involving

keeping “bad news” from the patient, justifying that it was better they did not know, as often they would have no control over the outcome. Today, it is unethical and illegal to withhold medical information; yet, there is a feeling among these families that therapists are not always honest about the possible outcomes. Many parents felt that they had been misled by both physicians and therapists in the past. One of the reasons many people say they respect Ramón as a therapist so much is his honesty and that he can be trusted. He is honest, bordering on blunt, regarding what he thinks that the child’s future looks like in terms of what his therapy can do for their mobility.

The paternalism of the past that may have extended into dishonestly to “protect” the patient or so not to worsen the child’s situation is not present with Ramón, as acting in the role of a father figure he is also very upfront with his prognoses. One of the mothers, who has been told that CME will not enable her daughter to walk or improve mobility, but instead can only maintain the mobility that she has now, decided to stay and see Ramón anyway. This illustrates the truthfulness and trust between Ramón and his clients, and their trust in him to help their children; if he cannot help in the way he would like (help them walk), then he will be very upfront about it.

Outside of therapy, Ramón is also consulted for the occasional life crisis issue or even just small daily needs or problems. Upon arrival in Chile one of the mothers, Rita, reached the apartment she had set up to rent and the landlord refused to allow her into the apartment because she is Muslim. Unsure about what else to do, she phoned Ramón indicating that she was leaving to go back

home, to Canada. Ramón talked with her and found another family (orthodox Jews) for her and her son to stay with, at least until a suitable living arrangement was made. Ramón then transported this mother and child and brought them to the temporary housing situation. After finding another place to live, Ramón helped her to move her possessions as she had no vehicle and connections in Chile. On yet another occasion, a mother was in need of a dentist for her son and she was unfamiliar with the medical/dental system in Chile as well as the language. Ramón's daughter, Claudia, made a dentist appointment for her son and accompanied them to the appointment as a translator of sorts. On another occasion, Janet, (one of the mothers) was looking to purchase a home. She was using the office to make connections with the realtor, through both their telephone and fax, while also utilizing Ramón and Claudia's knowledge of the housing market in Chile and relying on their advice on moving forward with the deal.

The aspects of paternalism (and community as we shall see later) are most evident with the CME therapy families who have been in Chile for a long period of time. One of the ways in which Ramón's paternalism is demonstrated through gendered care giving. The casual way in which the office is run, the closeness between Ramón and his clients, and the absence of fathers (in most cases), allows for a flourishing paternal relationship.

Gendered care giving

Another way that the paternalistic healer-patient concept is relevant is that most of the parents accompanying the children to Chile are mothers, essentially offering an ideal opportunity for a paternal healer to be accepted. All clients' mothers were present in Chile and only two fathers were present full time (one father came to visit, another had plans to visit soon). All of the mothers included in this ethnography are the sole caregivers for their children. Only one of the nine mothers worked outside the home and the rest are stay at home, full-time caregivers of their children. The one mother who works outside the home for pay is employed at a nearby Jewish school alongside her husband and all three of their children attend the school where they are both employed. Many of the mothers had careers prior to the birth of their children. One mother, Janet, was a production manager for films; another, Rita, was in her third year of college when she left to take care of her son. With the exception of one who is in school, all of the fathers work "to support the family." Lucy, in a discussion of how her family is able to afford living in Chile and Ramón's therapy, said that they were in debt. She went on to talk about how she was uncertain how much debt they were, but was certain that her family is in debt because of their decision to move to Chile. When she and her husband decided to move to Chile, she told him that he was to take care of the finances, if she was going to take care of the kids and therapy, that he needed to manage the finances himself. Within this community, the responsibilities for childcare are reminiscent of years gone by when the ideology

of the mother to tend the child and the father to work to support the family (at least among the white middle class), was prevalent.

The care-giving trends within this small sample of families are consistent with the overall trends in families with children with severe disabilities. Dowling & Dolan find that mothers of children with disabilities are less likely to participate in the paid workforce, although many might like to become employed outside the household (2001). Donovan et al. (2008) establish that women are more likely to take leave, or work at home or part-time, citing numerous studies. They find that “the occupational performance of mothers of children with disabilities is constrained by time, overlaid by difficult emotions, and involves a desire for increased social contact” (Donovan, VanLeit, Crowe, & Keefe, 2005, p. 249). Research on working families shows that women and especially mothers are often disconnected from the work force through lack of policies sensitive to family issues (Gornick & Meyers, 2003); this can be further complicated through having a disabled child.

The “choice” to stay home with children with severe disabilities is sometimes one with serious consequences. For many of these parents it is not so much a choice but an obligation (Porterfield, 2002). While there is a great deal of literature available on mothering children with disabilities, some research completely overlooks the father’s role, suggesting the mother is the only parent responsible for the childcare of their disabled child (Horton & Wallander, 2001; Wallander & Noojin, 1995). While these families represent what some would call traditionally gendered parenting at home, for many of these mothers being

abroad offers respite from many “housewife” and “stay at home” mother activities. One mother, Lucy, expressed relief in not feeling like she “had to have dinner on the table at 6.” While there was clearly relief for a number of mothers, one mother, Allegra, indicated that she has a great deal support from friends in Canada, with no mention of her daughter (Willow’s) father. Another mother, Jessica, commented that when at home, she or one of her friends accompanies her son Nicholas to therapy (not his father). The support of friends and family is clearly an important aspect of parenting a child with disabilities, and this support is supplemented in Chile with other families and Ramón’s organization.

What then is the role of fathers currently in the lives of children with disabilities? In a study by Parish (2006) one of the key hindrances preventing mothers of children with developmental disabilities from working outside the home was the lack of task sharing on behalf of their spouses or partners (Parish, 2006). Looking now to the specific population of those included in this study, when in Chile, there is no expectation of the father’s responsibilities; often it is to be at home (in the home country) earning money. While there are circumstances under which mothers felt frustration at the father’s absence, on the whole, many felt as if it was a good set-up. In examining the breakdown of tasks within the household among parents of a child with disabilities, Heller, Hsieh, and Rowitz find that fathers of disabled children do not necessarily provide more care to their child (children) than a father with a typically developing child (1997). They found that the mothers are more (than men) responsible for care-giving tasks, helping the child, household tasks, support for child, and worked less outside the home.

Whereas the fathers were found to be more (than women) responsible for providing financial assistance (Heller et al., 1997). In families where a child with disabilities is present, families tend to be more traditional in their behaviors and task sharing (Heller et al., 1997; Olsson & Hwang, 2006).

In looking at mothering, some research has shown that mothers often feel guilty about going into the workforce. Shearn & Todd (2000) argue that “For some women, the decision to have children entailed a personal subscription to the idealized model of the ‘good mother’” (Shearn & Todd, 2000, p. 119). This notion of “being a good mother” for mothers in this study is felt in two ways, feeling guilty themselves and feeling like others look at them as “bad mothers.” This notion of good/bad mother can be especially harsh for women whose children have disabilities. Blum (2007) found that mothers of children with invisible disabilities like those of children with visible physical disabilities encounter “mother-blame.” In addition, she calls the mothering technique these mothers are using “vigilante,” meaning “the intensified monitoring of the child and oneself and the need to take the ‘law’ into one’s own hands when advocating on behalf of one’s vulnerable child” (Blum, 2007, p. 212). The mothers in this ethnography are akin to those that Blum (2007) is referring to. While these mothers have no control over the inner workings of their child’s mind and body, they do have control over those who they engage to help their child, to treat their child. These mothers have hand-picked Ramón for their child’s therapy as a form of this “vigilante” mothering.

Brandon (2007) found that mothers spend more time with their child with disabilities than do the fathers. In addition, the mother has less time for herself and a social life than does the father (Brandon, 2007). This finding holds true of the mothers within this sample. The mothers discussed in this thesis are cases that represent an extreme case of these gendered divisions of parenting. These are extreme cases because the mothers have decided to move away from their homes to access a therapy they deem necessary for their child.

What about when daddy is in town? One of the clients fathers comes to visit in Chile often (Lucy's husband). When we were talking about what that is like, she seemed slightly torn. On the one hand she loves to see him and the kids go absolutely crazy over him. He provides the fun stuff, lets the kids skip school, and takes them to the park. On the other hand, she finds it a little frustrating because, she states: to have five kids in Chile by myself requires a routine and then when he comes, it takes weeks to get back into that routine. The fathers having the "fun" work while the mothers continue to do the childcare and housework mirrors Hochschild's (1989) argument in the *Second Shift*, in that women do more maintenance work and men do the "fun" stuff like going to the zoo and the movies (Hochschild, 1989).

When asked about the difference between being in Maryland and being in Chile, Lucy felt that there was no real difference in the amount of childcare she took on within the family (all of it), and stated that the housework is actually less in Chile because she has a housekeeper. In this case, the physical absence of the father made no difference to the mother in terms of how much she takes care

of within the household. In fact, only one of the women felt that they had increased responsibility for childcare or housework while living in Chile away from their child's (children's) father.

In discussing the part of Rita's husband in caring for the child, she responded:

“Actually, currently my husband is out of this whole thing, he has been going through a depression since [our son] was born, so we dealt with the situation in a completely different way, he has no idea what's therapy, he has no idea what is the difference or anything at all. Um, he, um, so it's basically only me.”

Clearly, in this isolated community, the pattern of women at home with the children and fathers in the workplace is salient. Williams states: “Women still specialize in family work. Men still specialize in market work” (2000, p. 3). These women seem to exaggerate the oppressiveness of gendered childrearing. They take on all the daily work of raising a child with a disability, while the father is thousands of miles away. Though these women take on extreme care-giving, there is a paradoxically liberating aspect of the circumstances as we saw through the mother's relief of other routine obligations, greater control over their day-to-day lives (with the exception of scheduling around Ramón), as well as the crucial social supports from other families and Ramón's organization. I found that a majority of parents indicated that they agreed with their spouse (or child's parent) on therapy decisions, but for two cases, the mothers felt they were the experts and their opinion mattered above all. When asked about agreement or sources of

disagreement between her and her ex-husband over decisions about their daughter, one mother stated:

“We are pretty much in agreement on the most part (on issues regarding the child's therapy and medical treatment)... it's a different kind of dynamic because everyone comes to the table with of course their different perspective and in parents typically and especially in children who are special ...there is going to be one and its, usually the *mother of who is more hands on* and (one) who is in supportive position because someone-life, someone needs to go to work and make money to support therapy and life, and typically in life even without special children this is the father unless the mother has some kind of career...”

She maintained: “... typically it's the Mommy's who knows like exactly what's going on with their kids, you know...” These mothers were proud that they were the caretakers of these children, and these women clearly stated that it was their place to do so. The mother quoted above, Janet, felt that mothers had a special connection with their children, which applied especially with her child (and many other clients present in Chile), since her daughter is non-verbal and she relied on this connection for communication daily. There was very little indication that these women felt as if the situation was “unfair” in anyway, where there was discussion of how some extra help could certainly make things easier.

The actions that these mothers take to encourage their children's nourishment beyond their natural development have been called ‘concerted cultivation’ (Lareau, 2003).

Concerted Cultivation. In *Unequal Childhoods*, Lareau explores “concerted cultivation” as a form of parenting in which middle class parents (mothers, although there is no specific conversation about gender), “deliberately try to

stimulate their children's development and foster their cognitive and social skills" while for poor families natural development is deemed a success. The outcome of these two parenting types is the "transmission of differential advantages"(Lareau, 2003). Those children of upper class families are passed on tools beyond their natural developments because of their parents' choices of activities for their children. Parents in these upper class families are actively engaged in "cultivating" and enriching their children for their futures, while those of the lower classes are helping their children make it on their natural path often without the enriching tools of their upper-class counterparts.

How then does this translate into these extreme cases of children with disability living abroad? Through concerted cultivation, mothers are working extremely hard to transmit success to their children, although through very different means, through access to therapy designed to enable them to walk. Applying Lareau's "concerted cultivation" parents of limited means might be happy with the outcome of their child being happy and in a well fitted wheelchair. The parents in this study, upper class white families are taking their child's development into their own hands. While Lareau discusses piano lessons and baseball practice as building cultural capital for children (Lareau, 2003), the mothers in the current research (all middle or upper class) are building up their child's capital and likeliness of success through seeking the "best" therapy for their child, even if it is on the other side of the world.

All of these mothers take on the charge of being the primary caretaker of their child (children), and these mothers take pride in that they feel that taking

care of their children is something that they are responsible for, and can therefore do it best. These mothers are the primary caretakers of their children when they are in the States and in proximity to the fathers, as well as when they are in Chile. These mothers are actively engaging in cultivating their children's futures, trying to ensure that their lives are as "normal" and full as possible. One mother, Lucy, mentioned that she and her husband, in a conversation of the money it takes to be here, said that they would feel terrible if their child had the opportunity to walk and they had not given it to her because of the cost. Her husband came for the first time to Chile to "check out Ramón" and Lucy has taken Daisy on all subsequent trips because her husband has to work in the states.

The active pursuit of tools for your child to succeed was evident in these women. Some referred to this as wanting their children to live a "normal life." Others maintained that if their child has the potential to walk, or to be more mobile, then they would do anything to help the child achieve that potential. In addition to knowing "what is best," these mothers take an incredibly active role in creating opportunity for their children to succeed through what Lareau might call "concerted cultivation"(Lareau, 2003). This mirrors Lareau's concerted cultivation argument as these children had therapy at home whether through their school or through their social services. Although these children had a natural path (akin to Lareau's "natural growth") to growing up, and had other less desirable options, the mothers feel that an investment in this therapy is necessary for their children's' success. Through this move and this mothering, these women have

also found an increased sense of self-worth through their actions as mother and also through a sense of accomplishment in moving across the world and successfully adjusting. One mother, Rita, who had a lot of resistance from friends and her husband about coming to Chile, found herself not only able to survive in Chile “alone,” but has thrived and found personal success through her child’s success in therapy. Lucy, who moved to Chile with her five children and two dogs, felt a sense of accomplishment in adjusting to life in Chile and also found ways of adapting and dealing that might not be as tolerated (even to her) in the states. She gave an example of driving her mini-van she purchased since moving to Chile and how after going too close to a wall in a parking garage; she had scratched the entire side of the van. She exclaimed that it would have been such a big deal at home, and here, it didn’t bother her at all.

While engaging in modern practices of seeking out health care options, these families are simultaneously engaged in a select type of physician-patient relationship that is reminiscent of the past, including a paternalistic leader. The paternalism fits into the equation in that these families all consist of mothers who are the primary caregivers of their children. Being away from their typical daily lives and with a paternalistic healer has shown to be, in some ways, paradoxically liberating. While the physician-patient relationship appears to fit this relationship with modern caveats, it is important to look from other perspectives to better understand Ramón and his relationship with his clients.

Is the physician-patient relationship a good fit?

While in the mid-20th century there was typically a town or family doctor and few other options, today the options are endless, if you can afford them. The influx of medical consumerism in the 1970s (Starr, 1982) means the patient is seen as a consumer and has the choice of which health care practitioner to see (Potter & McKinlay, 2005). While the interaction between Ramón and his clients is reminiscent of the past, how the patients came to see Ramón and their choice to stay with Ramón is a reflection of the modern health care industry. Today's health care system is characterized by managed care, corporatization, and technology driven innovation (McKinlay & Marceau, 2002; Potter & McKinlay, 2005), and does not seem to fit Ramón's practice into the mainstream medical model. While the physician-patient relationship of the mid-20th century is a near fit with modern caveats, I turn now to alternate frameworks/explanations including complementary and alternative medicine, faith healing, and medical tourism, to see if there are other areas or paradigms offering a greater understanding of Ramón's successful international following and maintenance of this unique organization and resulting community.

Complementary and Alternative Medicine. In order to correctly classify if CME therapy fits within the realm of complementary and alternative medicine (CAM), it is important to understand what CAM is. CAM is defined as: "medical practices that are not in conformity with the standards of the medical community... medical interventions not taught widely at U.S. medical schools or generally available at U.S. hospitals" (Eisenberg et al., 1998). There are many

types of CAM available, some of which are chiropractic care, acupuncture, homeopathy, and the use of herbs (Eisenberg et al., 1998). Researchers have found that people who use complementary and alternative medicine use it alongside conventional medicine (Druss & Rosenheck, 1999; Eisenberg et al., 1998).

The growth of complementary and alternative medicine is evident. The extent of popularity of CAM was confirmed in 1995, when Eisenberg published an article in the *New England Journal of Medicine* about the prevalence of using CAM and costs associated with its use in the United States (Budrys, 2005). Eisenberg found that one-third of Americans were using some form of CAM (Budrys, 2005). Does Ramón's therapy fit within the spectrum of Complementary and Alternative medicine?

One of the first questions that I asked Ramón, the founder of this therapy, was regarding how he would classify his therapy (CME). He stated that he would not in any way classify his therapy as CAM because that suggests that it is secondary to a primary therapy. He went on to say that his therapy is the core of what a child needs for physical therapy (in stark contrast to NDT "traditional therapy"), but is *not* to be considered as an optional addition to another treatment. Ramón sees his therapy as a necessary primary therapy for children with mobility difficulties.

One of the issues in classifying therapies as CAM is that the criteria for being a complementary and alternative medicine is quite unclear other than

being outside of mainstream medicine. Because CAM therapies are often used alongside other “primary” care treatments, this might indicate that Ramón was right in his assertions that CME does not fit under CAM classification. CME therapy is akin to NDT therapy (accepted worldwide and taught at Universities as the main form of physical therapy), the differences being that CME is not as widely recognized or known, and that training for CME comes directly from Ramón, often after formal schooling or training. While many “unorthodox” treatments are categorized as such because they are not certified within biomedical standards and schooling (Gevitz, 1988), this is not the case for Ramón as he is a certified (Classically trained) Physical therapist in both Chile and Canada. One commonality between Ramón’s clients and those who seek out CAM is the questioning of limitations of biomedicine or mainstream medicine, though Ramón’s clients use exclusively CME and most of those using Complementary and Alternative do so in addition to other therapies, including CME.

Faith Healing. Often, when I recount the situation of Ramón and his clients, people say, “well that sounds like a faith healer, is he religious?” While CME is not based on a religious foundation, there are similarities with faith healers of the past. Briefly I will discuss how faith healing tradition might relate to Ramón’s organization and how CME and Ramón are not within the faith healing framework though it may appear that way to a casual onlooker. The notion of a physical therapist that is worth traveling the world for often instills ideas of “faith healing” or questions as to what this therapist has that is worth the trouble of

travel, expenses, enduring the emotional roller coaster of the uncertain promise of mobility. Faith healing is “in most religions, a tradition of miraculous cures brought about by the touch of prominent individuals, contact with a sacred relic, amulet, or place, anointing with sanctified oil or water, or any other medium presented by charge or intent to the ailing” (Randi, 1987, p. 13). Ramón’s clients do not believe that merely through his touch, their child will walk. Instead they believe that through his therapy, as exercised through him, their child might learn to walk. There is no shrine or sacred totems or medium through which Ramón heals. The main way in which Ramón is expected to heal is through his unique physical therapy methods, specifically designed to reeducate the brain. CME therapy is mainly within the biomedical realm, and although it is in opposition to mainstream therapy in its theory and execution, it does share in its premise as to what causes illness and wellbeing. The main goal of both therapies and the health and illness field as a whole is to cure the patient, in this case enable these children to walk.

Ramón’s international client base began in a Jewish community in Canada and proceeded to spread through word of mouth. The result of Ramón’s first traveling clients being a part of a Jewish community led to a client base highly concentrated with Jewish families. One father from Israel, whose daughter, Miriam, contracted Meningitis (and resulted in her inability to walk), asked me why I thought that there were so many Jewish clients who saw Ramón for therapy. He stated that he thought it was strange and did not expect to see such a high proportion of Jewish families. This interchange indicates how little religion

or religious faith has to do with Ramón's therapy. There are no overt religious components to CME therapy.

It appears that therapy is of primary importance, even over religion in some cases, for these families while visiting Ramón. While many of the families are strict in their religious beliefs (ranging from Islam, Judaism, and Christianity), in some instances, like the one mentioned above of a Muslim woman staying with an Orthodox Jewish family (in Chile to see Ramón from the US), helping a friend or another in Ramón's community trumps traditional religious practices. On other occasions, there have been instances where religion or religious beliefs have been sidelined for the sake of therapy or therapy related goals. When I asked Jacob, a father from Argentina, who is an orthodox Jew for an interview, Ramón had mentioned that I should not be offended if he declines because I am a woman and I am not dressed appropriately (I was wearing long pants and a short sleeve shirt).

In addressing the question of religion, it is important to discuss one aspect that many people have approached me about regarding this phenomenon: "it seems a little cultish." While some of Ramón's clients attribute his gift of healing these children to God, his therapy (CME) has no visible religious components. Ramón does not use the basis of religion to encourage or discourage children and their families from coming, only the criteria of whether or not he can help their child. While there are no common religious aspects of the therapy, Ramón is very accommodating to the various religious beliefs of his clients. For example: during sessions families are able to play whatever kinds of music they like and

they often sing songs (in Hebrew or otherwise). There are aspects of Ramón's organization that appear religious, and I attribute this to his charismatic personality and healing, such qualities (which are discussed in the Charismatic healing section) and also to his paternalistic presence. When I asked one mother, Lucy, how she would classify CME therapy, she stated: "Only therapy that we have tried that really seems to me to be based on logic... There is nothing hocus pocus about it."

Medical Tourism. Is following Ramón merely a reflection of trends in medical tourism? Recent trends in medical tourism or traveling abroad for medical procedures have been on the rise. People have traveled abroad for medical treatments for centuries, however, today with the increase in accessibility to air travel, globalization, advances in technology and the Internet, high cost of health care, and long waits for medical procedures in some places, medical tourism is on the rise. Today it is much easier to travel abroad for any reason and this certainly contributes to Ramón's success (if transportation were not so accessible worldwide, Ramón's client base would certainly be different). The motivations for traveling abroad to see Ramón; however, are inherently different than the reasons for medical tourism.

A majority of medical tourists go abroad for a better price, a shorter wait, or to access therapies or procedures that are illicit or unavailable in the US (Connell, 2006). Ramón's clients are traveling abroad and paying out of pocket for therapy that could be covered under insurance in their native country. The families in this ethnography are quite different than most other medical tourists in

that they are seeking out one man to perform a specific type of therapy (which is available elsewhere around the world). While these families leaving home to see Ramón could currently be loosely classified as medical tourists, it does not appear that really explains the motivation for families going abroad for Ramón. While going to see Ramón can be classified as medical tourism (though not the same as current trends), the reasons many people go to see Ramón have to do with his unique style of therapy and his charisma. In the next section of this thesis I will look at Ramón's relationship with his clients as a paternalist and also his qualities as a charismatic healer.

The Charismatic Healer

According to Weber: “The charismatic leader gains and maintains authority solely by proving his strength in life” (Gerth & Mills, 1946, p. 249).

This section of this thesis will utilize the notion of charisma and charismatic healing to better understand how Ramón is able to create and maintain an international following. First, we will explore Weber’s concept of charismatic leaders, then apply this notion to Ramón and his following. Using this notion of charisma, we will then look to literature about the charismatic leader more specifically and if and how Ramón fits (or not) into the definition of a charismatic healer. Second, we will look to the community component of Ramón’s organization using Durkheim’s notions of collective consciousness and effervescence.

Viewing Ramón as a charismatic healer offers insight as to how he attracts, maintains, and grows a client base, and answers some of the lingering questions as to what it is about him that makes people travel the world. Weber’s notion of charismatic leaders, which says “The natural leaders in distress have been holders of specific gifts of the body and spirit; these gifts have been believed to be supernatural, not accessible to everyone” (Gerth & Mills, 1946) (245). Ramón trains other physical and occupational therapists through the four stage system described earlier, yet no one else is “Ramón” or holds the given gifts that he does. While Ramón can pass on his knowledge and new ways of

conducting physical therapy, no one else has the gift to perform the therapy and solicit the results quite like Ramón. Weber mentions doctors (along with judges, military leaders, and leaders of hunts) as being in a position by which they “practice their art by virtue of this gift (charisma)...”(Gerth & Mills, 1946, p. 246).

Thus, Ramón is an excellent modern day example of what Weber calls a charismatic leader. What is charisma? Weber defines charisma as “meaning literally ‘gift of grace’” (Gerth & Mills, 1946) (52). Employing Weber’s ideal types, it is clear that “pure charisma” (248) is not what Ramón represents; instead Ramón’s position is a mix of charismatic and paternal (the paternal aspects were discussed in detail in the first section of this thesis). Weber defines a charismatic leader as “self-appointed leaders who are followed by those who are in distress and who need to follow the leader because they believe him to be extraordinarily qualified” (Gerth & Mills, 1946)(52). Those in distress, in terms of Ramón’s charisma, are the families of the children dealing with severe physical limitations who are seeking for a therapist that can do what no previous therapists have accomplished with their child. All the parents have stories of seeing other therapists and it not feeling right, of seeing doctors and knowing their plan wasn’t the right solution for their children.

In his description of charismatic healers, Weber provides the example of political leaders and doctors. It is important to mention that Ramón is not an accredited doctor (medical or otherwise), instead he is a physical therapist with certification in Chile and Canada. When interacting with Ramón and the families

who are there to see him, you get the impression that he is “the best,” not through his self-confidence alone, but through the environment he creates, through the opinions of the parents of the children Ramón treats, and mainly through his charisma. The last question that I asked Ramón during our interviews was: what sets your patients apart from those who decide not to come to Chile? He answered that those who decide to come have a “conviction that I can help them.” He goes on to say that he only wants to help children walk and that he would not pressure anyone to come to Chile because in his work, there are no guarantees, except that he will try his best.

During my interviews with Ramón’s clients, many of them stated that Ramón was the best therapist (some indicated on earth, some indicated above all others). When probed about what makes Ramón worth the trip, one mother from Canada states:

“...the difference that nobody else will ever have other than him, is because he is gifted is the choice of exercises. He is gifted; God gave him this gift and it’s like a computer in his brain telling him what to do and which exercise to choose, the other therapists they can learn all the exercises, they can have physical strength, they can have the experience but they will never have that, they will never have the computer that he was gifted to have to make them choose this exercise first, then this exercise second, then this exercise third... that succession that he does and he does automatically is the one that sends the right stimulation to the brain.”

Janet, another mother, when I asked her what makes Ramón worth the trip, replied that she would come to Chile even if she had a level three (next level below Ramón) at home because she needed Ramón, and only Ramón to work

with her daughter. She went on to say that it was his therapy yes, but that it was more than that, it is the support and energy that he gives when doing therapy with the child. In one therapy session with Willow, Ramón remarked about what he was doing, he stated: “you see what I do, I adapt to each child.” He further stated that you need to get the child to feel the motion and get them to react. Ramón is able to adapt to each of the children and their specific challenges with walking. This is one of the things that parents see Ramón doing without pause, without consulting a text; he is naturally gifted at working with children for therapy.

When I sat in on one therapy session, the mother decided that it would be best if her daughter received acupuncture for a cold that was coming on instead of physical therapy. Ramón agreed and he placed the needles in Isa. During the placement, Ramón and the mother discussed a recent publication advertising a course being offered combining CME therapy and NDT therapy. Ramón and the mother alike were outraged. Not only was the so called “instructor” combining two therapies that are in direct contradiction to one another, this instructor is not even certified to teach CME. Ramón and his clients take very seriously the certification process and also not allowing “just anyone to practice CME.” The mother worried that this could taint Ramón’s name and also that people would be fooled into thinking they were getting Ramón when really they were getting an imposter. This story, told many times from one mother to another, is an illustration of the revered esteem they hold for Ramón and the importance of not diluting his position as founder and healer.

A second way in which Ramón is different from other therapists is through empowering parents and building relationships between the children and parents. Through teaching the parents how to work on therapy with their children at home or during downtime, he is empowering them and allowing them to participate in informal cultivation, akin to reading and writing with a child after-school.

In the mid 1960s, according to Nisbett (1992), early intervention services for infants and children with disabilities began being studied and valued. The medical model is evident in this history. Therapies involved parents bringing children to hospitals and therapy took place in a separate room away from parents (Nisbet, 1992). In the removal of the parents from the therapy, the implication is that medical treatment is purely scientific and medical. Through Ramón's inclusion of the parents in therapy and his reliance on their follow-through in his absence, he further perpetuates his charisma. Throughout the trip there are opportunities for the parents to not only spot but also to participate in the therapy so that they are comfortable doing the exercises. During the last days of the families visit Ramón makes a video of the exercises for the families to follow through on when they get home (or when Ramón leaves). One mother remarked that doing therapy with her child facilitates an even deep bond between parent and child. The parents see Ramón as the best therapist in the world, and yet he builds their faith in themselves and reinforces their faith in him through trusting that his client's parents will follow through with his work.

Ramón takes the word of the parents above all else and empowers the parents to be a part of their child's therapy. When telling Ramón of the child's

ability and their health history, he looks right at the parents, he nods and takes notes, and he appears to truly believe them. Through accepting parent's words as they tell them without a professional referral or opinion, Ramón instills trust in his clients and they in him, casting aside the purely scientific notions of therapy. When Ramón first encounters a new child, his main concerns are what the parents have to say about the child's mobility and condition and how he is able to customize his work with the child in his own hands. If the child was seeing another CME therapist prior to their visit with him, often in the past, he has asked that therapist for an email on how the child is reacting and what types of exercises they typically engage in so that he can be better prepared to work with them. Ramón does not consult the child's physician nor any other type of therapist on the child's history. It is Ramón's belief that the parent is the best expert on the child.

The charismatic healer qualities of Ramón are so salient that while teaching other therapists (levels one through four) and the parents to use his home program with their children outside of therapy, they all still feel that they need *him*. The extremes that these parents go to in order to see him, through the travel expenses and leaving typical home lives, highlight the concerted cultivation aspect of mothering that was mentioned earlier. CME is advertised only through word of mouth and information on his website and yet, Ramón has more clients than he can see (especially when traveling outside of Chile), showing how he has satisfied his former clients and continues to build a following.

Motivation

Yet another important part of charisma and a charismatic leader sustaining their position is motivation. What is Ramón in it for? The motivation of a therapist is important to many of these clients. Weber's notion of a charismatic leader cites that a motivation of the leader cannot be economically motivated, but instead to prove strength through gift (Gerth & Mills, 1946). Ramón, like the leaders that Weber is referring to, is not in the therapy for the money, but instead to enable children to walk, to share his gift of therapy. One mother, Janet, stated: "His heart is full as we say... he is not one of those people that's doing it for the money." She describes her relationship with Ramón as "complete trust you know that you are here for the good reason and you can trust him completely and if there is something wrong he will tell you." Another mother states that one thing about Ramón that both she and her daughter felt was that Ramón's intentions were clear regarding the children, and those intentions are to help these children walk. A third mother, Rita, stated that Ramón is worth every cent and that it is clear to her that he is not here for the money. Ramón, when asked about the monetary aspects of his organization, stated that he is disgusted with people in the health care industry that are in it for the money. He went on to talk about how some health care professionals exploit children with physical disabilities. He said that some parents want him to see their children many times and day and that he always refuses if he feels that they will not benefit from it, or if they cannot handle it.

The patients' endorsement of Ramón as a charismatic healer is incredibly important, as in order for any charismatic leader, healer or not, to be successful it is necessary for their followers to believe in them and believe in their strength and ability to perform their gift. Rita called being with Ramón a dream come true when she states: "I allowed myself to dream again and my dream now is to be with Ramón all the time and to follow him wherever he goes, whether it is international tour or to come back here again." Other parents agree that CME is the right type of therapy and that because their children are "hard cases" that other therapists are not necessarily willing or able to help, they seek out Ramón. One mother, Janet, states: "because we believe in CME therapy and it's really helping her." She went on to say that, "obviously Ramón's therapy is a very very different and special therapy which the children really had surpassed in their outcomes for what they would be achieving in NDT therapy for instance and we can see that in a lot of kids." Ramón's charismatic healing authority is legitimized through his patient's endorsement of his therapy and through his successes.

Instability

Charismatic authority according to Weber is inherently unstable. There are two ways in which this is true of Ramón's situation. First, Ramón travels the world six months a year. If parents travel to see Ramón there is a great deal of instability in that they are always moving to see him. When parents have chosen to move to Chile full time to see Ramón there, they eventually (after 6 months), face the decision of following him elsewhere or to stay in Chile without him there (or even any other CME therapist). The community of families that have chosen

to move to Chile permanently are those that are most affected by this instability because they have the most invested in Ramón, and they are most dependent on him in their day-to-day lives. It appears that as soon or shortly after they are settled into a routine, it is time for Ramón to travel abroad for six months. On every trip to Chile, Kate and I discuss how when you are in Chile with Ramón you do not want to leave. While families know that eventually they will be leaving, for some sooner than later, often time leaving is difficult. The disruption that this instability causes is described in the disruption section with examples of how families deal with this.

A second source of instability is the temporal nature of the therapy (i.e. the therapy is only for children, at some point they will either no longer need therapy or they will grow out of CME as it is only for children). Children that continue to improve under Ramón's care often remain until they have met their mobility goals (typically walking) and no longer need to see Ramón. For those that do not improve, there is a great deal of uncertainty as to whether Ramón will continue to see them and/or if the parents should continue the investment in being in Chile if his therapy shows not clear benefit. For children who the therapy is helping and those that it cannot, there is always a point at which Ramón can no longer see them, making this relationship inherently unstable.

A final way in which Ramón typifies a charismatic healer rests on the physical arrangements of how people access his therapies. According to Weber: "In order to do justice to their mission, the holders of charisma, the master as well as his disciples and followers, must stand outside the ties of this world, outside of

routine occupations, as well as outside the routine obligations of family life” (Gerth & Mills, 1946, p. 248). In order to see Ramón for any period of time, an individual (or family more likely) has to travel to access his therapy. Since travel, often across the world, is necessary in order to access Ramón and his therapy, the families are taken away from their daily lives and their routines. They are removed from friends and family for a period of time while they see Ramón. This removal of other obligations enables the families to concentrate only on therapy and also enables Ramón to maintain his charismatic authority over the families. For example, when these families travel abroad to see Ramón for therapy, they are isolated from family obligation, and also family support. Being so far away from “home” leaves them to rely nearly exclusively on other families and Ramón and his organization for day-to-day routines. As shown in the previous section on the healer/patient relationship, the reliance on Ramón for day to day planning and the removal of occupational and familial responsibilities is characteristic of a charismatic healer. Gender and gendered care-giving illuminate Ramón’s charisma. Mostly mothers travel with their children to see Ramón, and through his paternalism and their reliance on him for daily planning (and especially with the removal of husbands and fathers from their immediate presence). The result of mother’s often traveling alone and Ramón’s paternalism is a dynamic relationship between the clients, their families, and Ramón built on trust and support which is essential especially for those mothers who are in Chile for very long periods of time.

To what extent does the absence of Ramón disrupt and reorganize lives? The amount of disruption clearly depends on the amount of time they plan to spend with Ramón. Lucy, when getting ready to head back to the States, had a very hard time adjusting to the change and the practical needs of moving back. She had been in Chile for nearly six months and had bought a home and enrolled her children in a Chilean Jewish school. Two days prior to leaving for the states, she called her husband and demanded his presence in Chile, explaining that she could not deal with their children on her own, with preparing to go back to the states, and the subsequent move. At that point she had four of five children in Chile with her (and her two dogs). In the days before Ramón's departure there was a frantic tone in the air while many of the parents were not looking forward to leaving, and yet two others elected to remain in Chile until Ramón returned. The frantic tone resulted from anxiety over anticipated competition for sessions abroad, as it is much harder to schedule with Ramón overseas (Belgium, Canada, Brazil, United States, etc.) because he is so busy. One mother so was nervous about going home, back to Canada, realizing that she had set up a new lifestyle here and was now forced back into the reality of the way it used to be. She remarked that she would need to get used to being back home with her husband and get into a new routine. Rita had planned on traveling and following Ramón from place to place in his six months of travel, but was nervous about finding the money to travel and after arriving she was nervous she might not be successful in scheduling sessions with him every day. Both families that were

staying in Chile had found homes and one family originally from Israel had found employment at a local Chilean school.

The charismatic community

Ramón's charisma is significant in and of itself: in addition, his charisma creates a community that takes on a life of its own. This community is one in which disability is normalized, one which has its own norms, and in some senses, its own ways of doing things. While Ramón is a charismatic healer, his following and the community that they create together are perhaps equally or more important. One outcome of this community is that social supports and networks are formed. Parents with children having severe physical limitations are constantly creating and recreating social support (as are parents with children without physical limitations but not to the same extent). The parents in this ethnography appear particularly challenged in terms of social supports because of the removal of their daily rituals and their family and peer support system. Ironically, and as Durkheim might expect, the community in Chile is creating and maintaining social supports for as long as that community is intact.

Social groups and communities, like the families seeing Ramón, are able to create things that individuals alone cannot, what Durkheim calls *sui generis* (Bellah, 1973). As individuals are inherently social beings, through being together and participating in rituals, the community can (and does) take on a life of its own. Independent of the individuals, the sum of the individuals and the community that they produce, as shown in Ramón's community has a life of its

own. In Ramón's community, the air of the community is one of acceptance of different ways of doing things and hence, normalizing disability. One mother who has been in Chile for over a year, has purchased a house and stays year round whether Ramón is present or not. On my last visit, Ramón commented that, "she is not just here for the therapy anymore." While Ramón was gone for six months, Janet called upon his son, Alex, to see her daughter "once in a while" and otherwise performed the therapy on her own. She found that while she wanted to have access to Ramón as often as possible, the travel back and forth was too hard on her and her daughter. On a different occasion, in referring to the craziness of their schedules and life in Chile, one mother remarked to Kate that she "could move to Chile, and they could start an insane asylum." While reflecting the chaos that was often experienced among these families in planning day-to-day events, through the community they found support and made light of those chaotic things.

Within this community, families were able to express their experiences in a community in which disability is normalized and in which there is a collective feeling of hope and wellness. When all these families come together for Ramón--a charismatic healer--a community is formed in which disability is normalized. Durkheim views charisma as social, this community illustrates how a community can create its own norms and also how it can create and recreate social supports which perpetuate those norms.

Conclusion: The Healer/Patient Relationship And The Charismatic Healer

Ramón's relationship with his clients is reminiscent of the Paternalistic doctor-patient relationship of the past. While the families who see Ramón for therapy have many options for therapy, they choose to travel abroad to access his novel therapy directly from him. His close paternal relationship is particularly unique because of the distance from their families and because of the typical lack of the fathers presence. In addition to paternalism, Ramón has charismatic qualities that enable him to attract and maintain a flourishing client base.

Ramón's charisma is both a quality of himself as an individual and the community that he and his followers together form.

PART IV- CONCLUSIONS AND IMPLICATIONS FOR THE FUTURE

This thesis contributes to the current literature on disability, mainly the fluidity of disability, taking a different direction than the existing narratives and applied work. In addition, this thesis provokes consideration regarding the direction of modern medicine, views on disabilities, and responsibilities for inclusion in society. This thesis has demonstrated how social context determines if a person is disabled or normal. When in an isolated community in which the norm is to be in a wheelchair and communicate differently, the constructions of disability and normality are temporarily challenged. Though small and isolated, this case study highlights the importance of community acceptance and understanding of difference. Through social support, different expectations, and physical and communication accessibility, this ethnography has shown that impairments are not translated into disability but instead into normality. Ramón is able to create and maintain this community through his charisma, paternalism, and his gift of therapeutic healing.

Part of what makes this conclusion so unique is that these families are not in Chile to join a community in which their child is normalized. Parents are seeking for their children to walk, to be more “normal” by mainstream medical standards. The goals of modern medicine are to treat or especially cure any abnormalities, sustaining the medical model of disability. These parents’

decisions to travel across the world, to enable their children to walk, support the tenants of modern medicine. Alternatively, these children within Ramón's community inadvertently highlight how modern medicine is socially constructed (what needs to be healed and what is normal) supporting the social model of disability. This community has been quite successful at normalizing disability through bringing together families seeking Ramón's novel therapy, a "medical" approach to cure children of their inability to walk. This paradox highlights the tension between the medical model and the social model of disability.

Through providing a social support network, fostering close relationships with his clients (and their parents) that are reminiscent of a doctor-patient relationship of the past, Ramón makes the stay in Chile comfortable and in some cases seemingly easier than when the CME families are in their home country. His paternalistic relationship with his clients and their families allows for a comfortable, "family" like feeling to the environment in which, Ramón can be called up in case of a crisis or even an everyday dilemma. Through his charismatic approach, Ramón is able to instill faith in his clients and attract families from around the world willing to traverse across continents in order to work with him. Ramón creates the community in which disability is normal and he supplies the structure for day to day routines that his clients and their families live by. His charismatic qualities contribute to his clients and their families' dependence on him and thus the disruption to their lives during his absence. Due to the instability of this community because of both the charismatic nature of

Ramón's position and his travel schedule, the adoption of "normal" for these children is only temporary.

The implications of this thesis are far reaching, certainly beyond the field of disabilities. Groups of people are placed at the margins of society because of outlying characteristics, or marks of difference; they are according to Goffman, stigmatized. Those marks of difference are neutralized in an isolated community, thus permitting those previously barred from full inclusion in society access to both physical and social opportunities.

The finding of this thesis support that "disability is simply one of many differences among people and that society should recognize this by adjusting its environment accordingly" (Garland-Thomson, 1997, p. 49). Returning now to the treatment and definition of disability addressed at the onset of this thesis, Quinn recommends that it is societies responsibility for the "removal or amelioration of social and environmental barriers to full social, physical, career, and religious participation" (1998, p. xx). In many ways, Ramón's community was able to achieve the removal of these barriers indicating that it is possible. Alienation in mainstream society is unnecessary for people who participate in different ways; for people who are unable to walk, employing inclusionary policies that do not encourage pitying but instead respect for different ways of functioning is necessary. This community has shown that through adjusting the environment, children experience normality and fuller participation in both physical and social activities.

The notion that inclusion for currently marginalized populations is a matter of social constructions and social norms implores further questions: Is it possible to recommend that Americans and others around the world change their notion of the way people should function, communicate, and act? Does acceptance necessitate a shift in the ideals that are important to us and how we achieve them? What are the actions that it would take to replace the emphasis on body strength and independence as qualifications for personhood and full participation in society for those lacking mobility for instance? What are the policy implications for those with disabilities and also for all human differences outside of disability? Future work could concentrate additionally on such questions, including: Are the normalizing aspects of this community simply a result of the scale? Is this community necessarily bound by the specific combination of Ramón's qualifications, innovation, and charisma? Could it exist with a different therapist? Additional research could study the community during his months abroad and also spending time with the families while they are at "home" could provide a good comparison study.

A question that arose that I believe this study could elucidate is: can notions of "normal" and of functioning bodies be changed by increased exposure to persons with disabilities? Perhaps increased exposure to people with disabilities would shift the notions of how they should be treated. However, people with disabilities should not have to win over people they meet, in order to challenge typifications and stereotypes about themselves as individuals as this question implies. As in the case of the community in Chile, the families and

children have internalized the norms of mainstream society, striving to achieve normality through coming to Chile and seeking therapy. These children experience normality in Chile; this is possible because they are from families with access to financial means which afford them access to this normalizing community. While they achieved normality within an isolated community, they continue to hold on to their old identities in the development of the new (i.e. they will know that they are still “disabled” in the real world even if normal in Ramón’s community) unless we change the norms and expectations of society as a whole. It is not enough to say that isolated communities and those who have contact with individuals with disabilities are only those who can accept and perhaps embrace individuals with differences as fully human. Persons with disabilities are considered through the medical framework and in many ways mainstream society a group with “something wrong” and something to be fixed. Changing the way society views disability will enable disabled individuals to live differently than others without the stigma now associated with disability. Individuals with “abominations of the body” or any other medicalized disability should be allowed to choose whether or not they want to be “fixed” without the pressure of society labeling and treating them as second class citizens.

Through shifting our notions of normality, those who are currently considered disabled would clearly benefit but so will those who are considered normal. After all, we are all disabled at some point in our lives whether chronic or fleeting. Having flexibility in the acceptable ways of acting and being could serve to benefit everyone. While it is important that people within society have options

for health and wellbeing, medical treatments for difference should be more of a choice than a necessity. These children should not have to walk and talk to be full members of mainstream society. They are fully human and deserving of participation in all aspects of social life in mainstream society, not just within an isolated community. To acknowledge that the barriers placed on these children and all those with “disabilities” are constructed by people, by society, is to acknowledge that it can be changed by people, by society.

REFERENCES

- Akerkar, Shashank M, & Bichile, LS. (2004). Doctor patient relationship: Changing dynamics in the information age. *Journal Postgrad Medicine*, 50(2), 120-122.
- Albrecht, Gary L. (Ed.). (1976). *The sociology of physical disability and rehabilitation* Pittsburgh: University of Pittsburg Press.
- Andreassen, Hege K., Trondsen, Marianne, Kummervold, Per Egil, Gammon, Deede, & Hjortdahl, Per. (2006). Patients who use e-mediated communication with their doctor: New constructions of trust in the patient-doctor relationship. *Qualitative Health Research*, 16(2), 238-248.
- Barsch, Ray H. . (1968). *The parent of the handicapped child; the study of child-rearing practices*. Springfield, Illinois: Charles C Thomas.
- Bellah, Robert N. (Ed.). (1973). *Emile Durkheim; on morality and society* Chicago: The University of Chicago.
- Berger, Peter L. , & Luckmann, Thomas. (1967). *The social construction of reality*. New York Anchor Books.
- Bloom, Samuel W. (1963). *The doctor and his patient*. New York The Free Press.
- Blum, Linda M. (2007). Mother-blame in the Prozac nation - raising kids with invisible disabilities. *Gender & Society*, 21(2), 202-226.
- Brandon, Peter. (2007). Time away from "Smelling the roses": Where do mothers raising children with disabilities find the time to work? *Social Science & Medicine*, 65, 667-679.
- Budrys, Grace. (2005). *Our unsystematic health care system* (Vol. 2nd edition). Lanham: Rowman & Littlefield Publishers.
- Car, Josip, & Sheikh, Aziz. (2004). Email consultations in health care: 2-acceptability and safe application *BMJ*, 329(August).
- Charon, Rita. (2004). Narrative and medicine. *N Engl J Med*, 350(9), 862-864.
- Connell, John. (2006). Medical tourism: Sea, sun, sand and ... Surgery. *Tourism Management*, 27, 1093-1100.

- Cotten, Shelia R., & Gupta, Sipi S. (2004). Characteristics of online and offline health information seekers and factors that discriminate between them. *Social Science & Medicine*, 59(9), 1795-1806.
- Cuevas, Ramón (2007). Cuevas Medek therapy from <http://www.cuevasmedek.com/index.html>
- Davis, Lennard J. (1997). *The disabilities studies reader*. New York: Routledge.
- Donovan, Mark J., VanLeit, Betsey J., Crowe, Terry K., & Keefe, Elizabeth B. (2005). Occupational goals of mothers of children with disabilities: Influence of temporal, social, and emotional contexts. *American Journal of Occupational Therapy*, 59(3), 249-261.
- Dowling, Monica, & Dolan, Linda. (2001). Families with children with disabilities - inequalities and the social model. *Disability and Society*, 16, 21 - 35.
- Druss, Benjamin G., & Rosenheck, Robert A. (1999). Association between use of unconventional therapies and conventional medical services. *JAMA*, 282(7), 651-656.
- Eisenberg, David M., Davis, Roger B., Ettner, Susan L., Appel, Scott, Wilkey, Sonja, Van Rompay, Maria, et al. (1998). Trends in alternative medicine use in the United States, 1990-1997: Results of a follow-up national survey. *JAMA*, 280(18), 1569-1575.
- Encyclopedia Britannica (Ed.) (2009) Encyclopedia Britannica
- Freidson, Eliot. (1970). *Profession of medicine; a study of the sociology of applied knowledge*. New York Harper & Row, Publishers, Inc. .
- Garland-Thomson, Rosemarie. (1997). *Figuring physical disability in American culture and literature*. New York: Columbia University Press.
- Gerth, H. H., & Mills, C. Wright (Eds.). (1946). *From Max Weber: Essays in sociology*. New York Oxford University Press.
- Gevitz, Norman (Ed.). (1988). *Other healers; unorthodox medicine in America*. Baltimore: The John Hopkins University Press.
- Goffman, Erving. (1963). *Stigma; notes on the management of spoiled identity*. New York: Simon & Schuster Inc.
- Gornick, Janet C., & Meyers, Marcia K. . (2003). *Families that work* New York: Russell Sage Foundation

- Groce, Nora. (1985). *Everyone here spoke sign language*. Cambridge, Massachusetts: Harvard University Press.
- Hansen, Nancy, & Philo, Chris. (2007). The normality of doing things differently: Bodies, spaces, and disability geography. *Tijdschrift voor Economische en Sociale Geografie (Journal of Economic & Social Geography)*, 98(4), 493-506.
- Heller, Tamar, Hsieh, Kelly, & Rowitz, Louis. (1997). Maternal and paternal care giving of persons with mental retardation across the lifespan. *Family Relations*, 46(4), 407-415.
- Higgins, Paul C. (1992). *Making disability; exploring the social transformation of human variation* Springfield: Charles C. Thomas.
- Hochschild, Arlie. (1989). *The second shift*. New York: Avon Books.
- Hong, Chia Swee, & Howard, Lynne (Eds.). (2002). *Occupational therapy in childhood*. London: Whurr Publishing.
- Horton, Trudi. V., & Wallander, Jan. L. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology*, 46(4), 382-399.
- Jadad, Alejandro R., & Gagliardi, Anna. (1998). Rating health information on the internet: Navigating to knowledge or babel? . *Journal of the American Medical Association* 279(8), 611-614.
- Lareau, Annette. (2003). *Unequal childhoods*. Berkeley: University of California Press.
- Longmore, Paul K. , & Umansky, Lauri (Eds.). (2001). *The new disability history; American perspectives*. New York New York University Press.
- Marks, Deborah. (1999). *Disability: Controversial debates and psychosocial perspectives*. London: Routledge.
- Marshall, Gordon (Ed.) (1998) *Oxford Dictionary of Sociology* Oxford: Oxford University Press.
- May, Carl (2007). The clinical encounter and the problem of context. *Sociology*, 41(1), 29-45.
- McKinlay, John B., & Marceau, Lisa D. . (2002). The end of the golden age of doctoring *International Journal of Health Services*, 32(2).

- Merriam-Webster (Ed.) (2009) Merriam-Webster Online Dictionary
- Meyers, Allan R., Anderson, Jennifer J., Miller, Donald R., Shipp, Kathy, & Hoenig, Helen. (2002). Barriers, facilitators, and access for wheelchair users: Substantive and methodologic lessons from a pilot study of environmental effects. *Social Science & Medicine*, 55(8), 1435-1446.
- Miller, Freeman, & Bachrash, Steven (1995). *Cerebral palsy; a complete guide for caregiving*. Baltimore: John Hopkins.
- Molloy, Harvey, & Vasil, Latika. (2002). The social construction of Asperger syndrome: The pathologising of difference? *Disability & Society*, 17(6), 659-669.
- Nisbet, Jan (Ed.). (1992). *Natural supports in school, at work, and in the community for people with severe disabilities*. Baltimore: Paul H. Brookes Publishing.
- Olsson, M. B., & Hwang, C. P. (2006). Well-being, involvement in paid work and division of child-care in parents of children with intellectual disabilities in sweden. *Journal of Intellectual Disability Research*, 50, 963-969.
- Parish, Susan L. (2006). Juggling and struggling: A preliminary work-life study of mothers with adolescents who have developmental disabilities. *Mental Retardation*, 44(6), 393-404.
- Parsons, Talcott. (1975). The sick role and the role of the physician reconsidered *The Milbank Memorial Fund Quarterly, Health and Society* 53(3), 257-278.
- Pearce, Christopher, Trumble, Stephen, Arnold, Michael, Dwan, Kathryn, & Phillips, Christine. (2008). Computers in the new consultation: Within the first minute. *Family Practice*, 25(3).
- Porterfield, Shirley L. (2002). Work choices of mothers in families with children with disabilities. *Journal of Marriage and the Family*, 64(4), 972-981.
- Potter, Sharyn J. , & McKinlay, John B. . (2005). From a relationship to encounter: An examination of longitudinal and lateral dimensions in the doctor-patient relationship. *Social Science & Medicine*, 61, 465-479.
- Prussing, Erica, Sobo, Elisa J., Walker, Elizabeth, & Kurtin, Paul S. (2005). Between `desperation' and disability rights: A narrative analysis of complementary/alternative medicine use by parents for children with down syndrome. *Social Science & Medicine*, 60(3), 587-598.

- Quinn, Peggy. (1998). *Understanding disability: A lifespan approach*. London: Sage Publications.
- Randi, James. (1987). *The faith healers*. Buffalo, NY: Prometheus Books.
- Russell, Marta. (1998). *Beyond ramps: Disability at the end of the social contract*. Monroe, Maine: Common Courage Press.
- Shapiro, Joseph P. . (1993). *No pity*. New York Times Books, Random House.
- Shearn, Julia, & Todd, Stuart. (2000). Maternal employment and family responsibilities: The perspectives of mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 13(3), 109-131.
- Shin, Jin Y. (2002). Social support for families of children with mental retardation: Comparison between Korea and the United States. *Mental Retardation*, 40(2), 103-118.
- Smart, Julie. (2001). *Disability, society, and the individual* Gaithersburg, Maryland: Aspen Publication
- Spock, Benjamin, & Lerrigo, Marion O. (1965). *Caring for your disabled child*. New York: The Macmillan Company.
- Starr, Paul. (1982). *The social transformation of American medicine*: Basic Books.
- Steinhart, B. (2002). Patient autonomy: Evolution of the doctor patient relationship. *Haemophilia*, 8(3), 441.
- Taylor, Shelley E., Sherman, David K., Kim, Heejung S., Jarcho, Johanna, Takagi, Kaori, & Dunagan, Melissa S. (2004). Culture and social support: Who seeks it and why? *Journal of Personality and Social Psychology*, 87(3), 354-362.
- Titchkosky, Tanya. (2003). *Disability, self, and society*. Toronto: University of Toronto.
- Tregaskis, Claire. (2004). *Constructions of disability: Researching the interface between disabled and non-disabled people*. London: Routledge.
- Wallander, Jan L., & Noojin, Ashley B. (1995). Mother report of stressful experiences related to having a child with a physical -disability *Children's Health Care*, 24(4), 245-256.

Wilde, Sally (2007). The elephants in the doctor-patient relationship: Patients' clinical encounters and the changing surgical landscape of the 1890's. *Health and History*, 9(1).

Williams, Joan. (2000). *Unbending gender: Why family and work conflict and what to do about it*. New York: Oxford University Press.

World Health, Organization. (2001). Disability. Retrieved June 21, 2009, from <http://www.who.int/topics/disabilities/en/>

APPENDIX A- GUIDING QUESTIONS FOR INTERVIEW WITH FAMILIES OF CME CLIENTS

Below are the questions that guided interviews with the parents of children receiving CME therapy. The interviews were not limited to the below questions, instead they were more of a guide for conversation.

Location

Where are you originally from?

How long have you been in Chile?

How often do you travel for the purposes of therapy?

Specifically for Ramón?

Do you have a MEDEK therapist where you are from? If not, does _____ receive therapy at the other location?

Where/ with whom do you stay with on these trips?

How did you hear about CME?

Family

How many children do you have?

Are you married? How long?

What does your spouse think of _____ seeing Ramón? Are there any areas of disagreement in terms of treatment for your child?

Who lives in the household with you?

How old is your child that receives treatment from Ramón?

What condition does he/she have and when did you first become aware of this condition?

Who typically brings _____ to therapy?

How does a trip to see Ramón typically work? What are the preparations that are involved in going to see Ramón?

Does Ramón set up the places for you to stay or do you have some other connections?

Do you consider yourself a religious person? What religion? In what ways?

Do you work outside the home? Does your wife/husband/spouse?

What are the roles that you and your spouse take on within the home and taking care of _____.

What is the highest level of education you completed?

What is a typical day like in your household?

What is a typical day like when you are visiting Ramón for therapy?

Past therapies

How long has _____ been seeing Ramón?

Did you participate in other types of therapy before seeing Ramón?

If you don't mind me asking, what happened with those other therapies?

How did you hear about Ramón?

CME

What types of changes has CME (MEDEK) made in your lives?

How is CME different than other therapies?

What is the outcome in your mind for _____ from this therapy?

What are things that Ramón does to make help your child (music, prompting, talking, touching)?

How would you classify CME therapy? Traditional, Non-traditional, mix?

What are the most important supports that you receive (prompt: family, religion, etc.)?

Who/what makes these trips (move) possible for you? (economic, religion, support)?

APPENDIX B- GUIDING QUESTIONS FOR INTERVIEW WITH RAMÓN CUEVAS, FOUNDER OF CME THERAPY

When did you start practicing physical therapy?

What is the path that led you to become a physical therapist?

At what point in your career did you start working on MEDEK?

How would you classify MEDEK therapy? Alternative? Complementary? Other?

When did you start to develop an international client base?

Approximately how many children do you treat in a year?

What are the demographics of the children/families that you treat?

Where are they from?

What types of motor delays do they experience?

Religious Affiliation?

Languages? Parents? Families? Communities?

Is it typically one parent or another who brings the child to therapy?

Always the mother? Father?

Is there a reason you choose to go to the counties where you go?

How is MEDEK different from other therapies? Compared to mainstream?

What types of clients do you treat? For example are there certain characteristics of those people that you treat that make them possible clients for you (health conditions, a good attitude....)

What is the process that you go through in meeting a new client? Is there a triage process?

Do you often have to turn people away from your services? Why?

How do people hear about CME (MEDEK)?

Do you take any types of insurance or discounts? What is the typical cost for families to come see you/ IN your understanding how do typically par for your services?

What is the role of CME (MEDEK) in the lives of the children that you treat?

In what ways does therapy go beyond the therapy room? Are there lifestyle changes or a role of parents that is important for this therapy?

What are the most important aspects of CME (MEDEK) in terms of success for the child?

What is a typical workday like for you?

What are the goals that you have for these children? Are they different for each child?

Do you alter the therapy session dependent on the child (if at all)? IN what ways?

What types of things are typically needed for families on trips to see you (cell phone, support)?

There is something different about CME (MEDEK) that makes people travel far and wide for your therapy, can you speculate as to what that might be?

In your experience how are the clients that seek out your therapy different from those who don't? Is there something about the people that you work with that makes them different than those that don't?

APPENDIX C- IRB APPROVAL FORMS

University of New Hampshire

Research Conduct and Compliance Services, Office of Sponsored Research
Service Building, 51 College Road, Durham, NH 03824-3585
Fax: 603-862-3564

05-Mar-2008

Vanderminde, Jennifer
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IRB #: 4216

Study: Social Supports and Alternative Physical Therapy

Approval Date: 04-Mar-2008

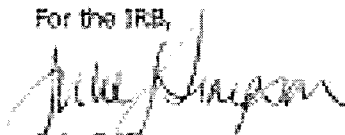
The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Expedited as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 110.

Approval is granted to conduct your study as described in your protocol for one year from the approval date above. At the end of the approval period, you will be asked to submit a report with regard to the involvement of human subjects in this study. If your study is still active, you may request an extension of IRB approval.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, *Responsibilities of Directors of Research Studies Involving Human Subjects*. (This document is also available at <http://www.unh.edu/osr/compliance/irb.html>.) Please read this document carefully before commencing your work involving human subjects.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,



Julie F. Simpson
Manager

cc: File
Blum, Linda

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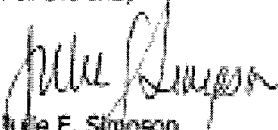
IRB #: 4216
Study: Social Supports and Alternative Physical Therapy
Review Level: Expedited
Approval Expiration Date: 04-Mar-2010

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved your request for time extension for this study. Approval for this study expires on the date indicated above. At the end of the approval period you will be asked to submit a report with regard to the involvement of human subjects. If your study is still active, you may apply for extension of IRB approval through this office.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the document, *Responsibilities of Directors of Research Studies Involving Human Subjects*. This document is available at <http://www.unh.edu/osr/compliance/irb.html> or from me.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,



Julie F. Simpson
Manager

cc: File
Blum, Linda