THE LIVED EXPERIENCE OF CARING: THE VOICES OF MOTHERS OF CHILDREN WITH DISABILITIES IN CARDENAS, CUBA

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ABSTRACT

Cuba’s community-based health care system is both internationally renowned and the signature of the Cuban revolution. Since the time of Cuba’s catastrophic economic crisis known as the Special Period in Time of Peace, the health care system has been closely linked to the state’s political legitimacy and the nation’s economic development. The Special Period also led to the state’s self-evaluation of institutional practices in health and social sectors. Lack of disability services and resources to meet the needs of individuals with disabilities and their families was a key finding of the state’s assessment.

The intent of this study is to present how, during Cuba’s Post Special Period, structure and culture come together to help in understanding the subjective experiences of women who care for their children with disabilities in a specific context, the community of Cardenas, Cuba. The experiences of women who mother their children with disabilities were examined through survey, semi-structured interactive interviews and observation of mother–professional interactions in the rehabilitation gym of El Centro de Rehabilitacion y Neurodesarrollo, the site where this study was conducted.

This study shows that structural and cultural conceptions of disability, gender, and the authority of health professionals are reflected in how mothers understand their children’s conditions, enact their roles as mothers, and navigate institutional arrangements. The dominance of Cuba’s health care within the society strongly influences the construction of disability as strictly a medical phenomenon. The
continuation of significant structural economic constraints clearly has an impact on the methods mothers use to gain resources for their children and access services. Cultural expectations that mothers with children with disabilities embody traditional “good mother” archetype contradict the state’s legislated position of gender equality.

This study reveals group differences in how mothers accept or reject the dominant discourse surrounding disability by examining how they explain their children’s conditions, the visions they hold for their children and their role in promoting their children’s progress. Within group differences are explained by individual location in the social structure and class. The three different approaches that mothers take on in the care of their children are described as provincial, community or cosmopolitan. These categories are distinguished by the mothers’ educational level, geographical location and their access to material and informational resources. We can conclude that Cuba’s economic crisis and a recovery plan that included capitalist initiatives played a role in augmenting economic stratification, resulting in a new but somewhat hidden class structure within this socialist nation. Thus the everyday lived experience of mothers who care for their children with disability in Cuba is influenced by the society’s structural and cultural arrangements.
ACKNOWLEDGMENTS

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Dedicated to my mother Kathleen A. Tupé and women everywhere who mother children with disabilities.
# TABLE OF CONTENTS

ABSTRACT ........................................................................................................................................... ii

ACKNOWLEDGMENTS ...................................................................................................................... iv

LIST OF TABLES ................................................................................................................................... x

LIST OF FIGURES ................................................................................................................................ xi

1. INTRODUCTION ........................................................................................................................... 1
   Experiences with Disability ................................................................. 5
   My Journey .......................................................................................... 8
   The Research Context ............................................................................ 19

2. CUBA’S HEALTH CARE SYSTEM: DEVELOPMENT AND EVOLUTION .................................. 23
   Foundational Principles ........................................................................ 26
   Cuba’s Revolutionary Health Care System: A Work in Progress .......... 34
   Structural Organization of the Cuban Health Care System .................. 44
   The Impact of Cuba’s Special Period on Health .................................. 50
   Cuba’s Evolving Health Care System: Global Health and Tertiary Care ........................................................................ 57
   Disability Services in Cuba ................................................................. 62
   Key Points ............................................................................................. 64

3. MOTHERS OF CHILDREN WITH DISABILITY: PERSPECTIVES, INTERPRETATIVE FRAMEWORKS AND SUBJECTIVE EXPERIENCES ......................................................... 68
   Structure .............................................................................................. 69
   Institutionalization of Disability ........................................................ 73
   Mothering a Child with Disability ...................................................... 78
   Gendered Caring for Children with Disability .................................... 80
   Conceptions of Motherhood: Context and Practice ......................... 85
   Conceptual Guide of the Literature .................................................. 89

4. METHODOLOGY .......................................................................................................................... 92
   The Research Setting: El Centro de Rehabilitacion y Neurodesarrollo ......................................................................... 93
<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td><strong>MAKING SENSE OF THE DIAGNOSIS: IDENTIFICATION AND UNDERSTANDING</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Noticing and identifying the problem</td>
<td>125</td>
</tr>
<tr>
<td></td>
<td>Naming the problem and understanding the diagnosis</td>
<td>132</td>
</tr>
<tr>
<td></td>
<td>Mother’s initial response to the diagnosis</td>
<td>135</td>
</tr>
<tr>
<td></td>
<td>Mother’s response to diagnosis at the time of the interview</td>
<td>142</td>
</tr>
<tr>
<td></td>
<td>How mothers make sense of their children’s disability</td>
<td>144</td>
</tr>
<tr>
<td></td>
<td>Advice</td>
<td>148</td>
</tr>
<tr>
<td>6</td>
<td><strong>MOTHERHOOD AND MOTHERING A CHILD WITH DISABILITY</strong></td>
<td>158</td>
</tr>
<tr>
<td></td>
<td>Families, Households and Relationships</td>
<td>159</td>
</tr>
<tr>
<td></td>
<td>The Everyday Experiences of Mothering a Child with Disability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Routines, Joys and Challenges</td>
<td>171</td>
</tr>
<tr>
<td></td>
<td>Caring for a child with disability</td>
<td>184</td>
</tr>
<tr>
<td>7</td>
<td><strong>FORMS OF MOTHERING: AGENCY, VISION AND THE GOOD MOTHER</strong></td>
<td>199</td>
</tr>
<tr>
<td></td>
<td>Mother and Therapist Interactions</td>
<td>202</td>
</tr>
<tr>
<td></td>
<td>The Observation Context</td>
<td>203</td>
</tr>
<tr>
<td></td>
<td>The Observations</td>
<td>205</td>
</tr>
<tr>
<td></td>
<td>Mothers’ Vision for their Children with Disabilities</td>
<td>208</td>
</tr>
<tr>
<td></td>
<td>Realizing the vision</td>
<td>212</td>
</tr>
<tr>
<td></td>
<td>Typology and Mothers’ Attitudes toward Rehabilitation Services</td>
<td>223</td>
</tr>
<tr>
<td></td>
<td>Interview Responses and Typology Categories</td>
<td>234</td>
</tr>
<tr>
<td>8</td>
<td><strong>CONCLUSION: OUTSIDE PERSPECTIVES AND INSIDE EXPERIENCE</strong></td>
<td>240</td>
</tr>
<tr>
<td></td>
<td>The Voices of Mothers: Caring for Children with Disabilities</td>
<td>247</td>
</tr>
<tr>
<td></td>
<td>in Cardenas, Cuba</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>BIBLIOGRAPHY</strong></td>
<td>254</td>
</tr>
</tbody>
</table>
APPENDICES.......................................................................................................................... 269

A. TIMELINE OF US–CUBA RELATIONS ............................................................... 269
B. TIMELINE OF DISABILITY SERVICES IN CUBA ......................................... 270
C. INTERVIEW GUIDE .......................................................................................... 271
D. QUESTIONNAIRE .............................................................................................. 275
E. GUÍA PARA LAS ENTREVISTAS ....................................................................... 286
F. CUESTIONARIO ................................................................................................... 290
G. OBSERVATION CODING .................................................................................. 300
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td>Evolution of Cuban health care system</td>
<td>42</td>
</tr>
<tr>
<td>2.2</td>
<td>Cuba general health indicators</td>
<td>54</td>
</tr>
<tr>
<td>4.1</td>
<td>Demographic profile: Survey demographic responses</td>
<td>119</td>
</tr>
<tr>
<td>4.2</td>
<td>Family support - Survey responses to maternal perceptions of family support in the care of their children with disabilities</td>
<td>121</td>
</tr>
<tr>
<td>4.3</td>
<td>Services received - Survey responses to services child and family received at El Centro</td>
<td>121</td>
</tr>
<tr>
<td>4.4</td>
<td>Services suggested by mothers - Maternal survey responses indicating services needed by their children and families that are not offered at El Centro or need to be enhanced</td>
<td>123</td>
</tr>
<tr>
<td>4.5</td>
<td>Mothers’ perceptions of rehab services and attitudes toward disability - Percentage of mothers who responded always to each statement. Other choices included most of the time or no.</td>
<td>123</td>
</tr>
<tr>
<td>5.1</td>
<td>Mothers’ perceptions of whether staff are willing to provide information</td>
<td>141</td>
</tr>
<tr>
<td>6.1</td>
<td>Distribution of person primarily responsible for child with disability</td>
<td>167</td>
</tr>
<tr>
<td>6.2</td>
<td>Distribution of person primarily responsible for the home</td>
<td>167</td>
</tr>
<tr>
<td>6.3</td>
<td>Distribution of family members help with care of the child with disability</td>
<td>168</td>
</tr>
<tr>
<td>6.4</td>
<td>Distribution of the family member who helps most with care of the child with disability</td>
<td>168</td>
</tr>
<tr>
<td>6.5</td>
<td>Distribution of responses to El Centro service delivery</td>
<td>169</td>
</tr>
<tr>
<td>6.6</td>
<td>Comparisons of interviewed/non-interviewed demographic data</td>
<td>172</td>
</tr>
<tr>
<td>7.1</td>
<td>Typology descriptions</td>
<td>218</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1. Cuban health care structure</td>
<td>46</td>
</tr>
</tbody>
</table>

xi
CHAPTER 1
INTRODUCTION

Seated in an audience of American educators, community activists and Cuban aficionados I settled in for a predictably lengthy speech that was the signature of Fidel Castro. This visit premiered Cuba’s newly established profession and School of Social Work to the American visitors. The School of Social Work was created in response to national social issues that became evident during Cuba’s economic crisis between the years 1989–1999. Prostitution, school truancy, older adults living alone and individuals with disabilities became national priorities during the nation’s Post-Special Period. The unexpected appearance of Fidel Castro, accompanied by American filmmaker Oliver Stone, highlighted the significance of the new school as the symbol of Cuba’s second revolution—“the social revolution.”

During the program presentation a young social work student who was introducing aspects of the nation’s newly formed social agenda was interrupted by Cuba’s President. The President jokingly stated, “Be careful my friend, Americans do not like the term revolution.” Fidel Castro went on to acknowledge the state’s limitations in meeting the collective social needs of its citizens as he framed the nation’s new initiative

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i The Special Period in Time of Peace is the term used by the Cuban government to mark Cuba’s catastrophic economic crisis during the years 1989–1999. The Post-Special Period covers the years 1999–current time.
within the historical context of the Cuban revolution. “I would say that we are in a later stage of development… a stage of social development… we are embarrassed by the things we have not done.”

This revelatory comment suggested Cuba’s willingness and ability to engage in self-assessment and to respond to sensitive national issues. The state was boldly offering a dramatic and ambitious vision that could in effect locate and provide social and disability services on a national level—a vision not fully manifested in many industrialized first world countries. Moreover, the labeling of this new initiative as “the social revolution” positioned its accompanying programs within Cuba’s historical narrative, called upon the support of the collective and reinforced the core ideological principles of the nation’s socialist structure and cultural values. Revolution, collective participation, solidarity and family are instrumental and revered threads in Cuba’s cultural fabric. Culture and structure come together in Cuba as one in communicating normative behaviors and institutional priorities.

The State’s first action in 2002, under the umbrella of the social revolution, was a national door-to-door campaign designed to count the number of individuals with disability in Cuba. Students from the School of Social Work were assigned to this task as they knocked on doors, negotiated unchartered terrain by boat and elbowed their way into back rooms to document each child and adult with physical or cognitive impairments. Disability became a National Priority Program adopting the spirit and symbolism of

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ii First world is a common, albeit outdated, label attached to nations that are democratic, industrialized, technologically advanced and have a high standard of living.
Cuba’s earlier health and literacy brigades. The construct of disability is an intriguing phenomenon. Structural conceptions of disability guide understandings and attitudes toward those with physical or mental impairment. Cultural knowledge and institutional arrangements are organized to both support and constrain the location of those with disabilities within the social context while impacting the everyday lived experiences of disabled individuals and their caregivers. The breadth of disability is noted in its presence in health, education, social and economic sectors of any given society. The personal experiences of those whose bodies are different from others provide understanding of not only the physical challenges of movement and functioning but also the values and principles of the society. Over the course of six years I had the opportunity to study Cuba’s disability programs from afar and witness the grassroots efforts of a children’s rehabilitation center in the Matanzas province, located two hours east of Havana. This privileged position led to more questions than conclusions and set the path for an investigation of experiences of disability as viewed from the vantage point of mothers of children with disabilities in the town of Cardenas, Cuba.

When looking at Cuba’s disability initiatives from a somewhat detached institutional or programmatic perspective the cumulative attributes of a centralized top down government are impressive. Disability policies are not bogged down by special interest groups or local governments’ resources or priorities. National campaigns and non-governmental organizations join together to communicate attitudes and actions expected of Cuban citizens in solidarity with all members of society who have disabilities. Cuba’s socialist structure, based on principles of social and economic
equality and core values of free and accessible healthcare and education, potentially provides a solid frame for a nationalized disability program. Cuba’s humanistic approach to health and respect for the human condition is pervasive, evident in professional interactions and widely accepted by healthcare providers and recipients of services.

However, it is when sitting inside the circle of disability that the complexities and contradictions of Cuba’s health, educational and social structures begin to emerge. Cuba’s humanistic approach to health is also extended to those with disabilities. When asked about the location of the disabled in the nation’s social fabric, a public health physician echoed a sentiment offered by others in response to the same question. “In Cuba all people are Cuban, we do not discriminate, we take good care of them” (PJ, Havana, 1/8/2003).

Implementation of Cuba’s National Disability Priority Program has indeed drawn attention to the presence of individuals with disability in various sectors of society. Individual interactions and remarks offered during my visits suggest that the participation of the disabled in Cuba’s social fabric can be messy, as the nation’s paternalistic approach to caring may obfuscate genuine acceptance and full inclusion.

The historical and socio-political context of Cuba provides a singular and unique setting to explore notions of disability. Issues of structure and agency become natural topics of interest and lead to questions about the role of Cuba’s socialist ideology in supporting or constraining collective and individual experiences of disability. Cuba’s prominent health care system can be reviewed as the most significant outcome and outstanding symbol of the Cuban revolution. However, the location of people with
disabilities within the nation’s health care system is barely visible as rehabilitation services are underdeveloped and difficult to access. Cuba’s socialist framework is grounded in the principle of equality for all individuals, regardless of gender, age, race and socioeconomic status. But the disabled body is a very salient representation of difference, of the other. The examination of this construct of physical disability within this specific socio-cultural context is particularly interesting. The events of the Special Period have not only drawn attention to the presence and needs of those with disabilities, they have also provoked questions surrounding the nation’s support of its most vulnerable citizens during this new era of social development. Of particular importance is how those with disabilities, their families and their caregivers experience everyday life and make sense of disability during this time of Cuba’s second revolution, the “social revolution.” This research seeks to explore these general questions through ethnographic study of a specific group, mothers of children with disabilities in Cardenas, Cuba.

**Experiences with Disability**

My interest in disability predated my curiosity in Cuba. At a very young age I became acutely aware of people with disabilities. The adult male on crutches swinging his left leg as his right pant leg was rolled up and pinned on his hip, the teenager in a wheelchair pushed by his mother as his legs and arms were contorted and not useful to the task at hand, the young boy whose glazed eyes revealed his loss of sight, were each strange and frightening to me. I often looked ahead, planning my route while walking through my public apartment complex to avoid any encounters. Yet, ironically I was a
child with a disability. At the age of five years I was diagnosed with juvenile rheumatoid arthritis. The management of this disease required prolonged absences from school, accommodations when in class and the social isolation and stigma attached to being different. My arthritis remised in my teenage years and I went on to college and graduate school becoming an occupational therapist working with children with disabilities.

My mother was 25 years old when she assumed the responsibilities of caring for a child with physical limitations. Accessing medical specialists, acquiring additional medical insurance, navigating educational systems, managing daily medications, keeping track of appointments and caring for two younger children were more than a full time job and most probably a lonely endeavor. My mother’s daily routines were subject to a shift in priorities and perhaps displacement of her own interests. When I was able to attend school, my mother with my younger sister in tow would bring lunch to me on my third floor classroom, as I was not permitted to walk up and down the stairs. My mother was required to navigate the bureaucracy of New York City’s educational system orchestrating my transfer from parochial to public school to qualify for home schooling. She acquired the medical knowledge needed to manage my condition without the benefit of televised health information or the Internet. When looking back on my mother’s experiences—during the time before the American disability rights movement, before the passage of the Education of Handicapped Children Act (now known as the Individual with Disabilities Education Act), and before the Americans with Disabilities Act—they seem similar to the stories shared by the mothers interviewed in this study. The mothers in the study are new to the world of disability, disarmed by their lack of information,
unfamiliar with institutional procedures and faced with limited assistance in understanding the implications of their children’s conditions.

Throughout my practice as an occupational therapist I have had the privilege to know many women who dutifully and caringly brought their children to therapy appointments. They administered prescribed regimens and tried to make sense of the world of disability and their own experiences. Many of the mothers welcomed me into their homes and shared pieces of their stories—their narratives—as we worked side by side to help their children gain the skills needed to reach for a toy, drink from a cup, pull on a sock or play with a sibling. Some women openly related their struggles, their worries, and their realities: loss of a profession, marital stress, gendered expectations, broken systems and social isolation. The lives of the mothers I came to know reflected the variety of experiences reported in the academic discourse surrounding disability. Some women reconstructed their identities as mothers. Others spent a large amount of time collecting the cultural capital needed to access services. Mothers were deliberate and attentive to their children’s clothing in an effort to dampen the stigmatized glances that marked their child as disabled. Women took on the role of advocates and struggled with depression and limited support (Green, 2007; Landsman, 1998; Larson, 1998; McKeever & Miller, 2004; Shapiro & Tittle, 1990).

As I matured in my professional practice I began to understand the importance of mothers’ knowledge of their children’s disability and their ability to be agents in the success and inclusion of their children in educational and social environments. Working with families whose backgrounds cut across ethnic and social class categories I became
more keenly aware of the impact of culture and social structure on the roles and practices that mothers adopt in negotiating the care and social location of their children. My particular interest in the experiences of mothers of children with disabilities developed further over the course of seven visits to Cuba between 1999 and 2006.

**My Journey**

I first arrived in Cuba in November 1999, two weeks before the story of Elian Gonzalez hit the American media. Gonzalez, the seven-year-old Cuban boy from Cardenas, was found adrift at sea by the United States Coast Guard on Thanksgiving Day. The American public and government officials were consumed with the modern day *novella* that dominated and politicized our conversations, providing the nation with a quick tutorial on Cuban-American history, policy and ideology. Elian became the living symbol of the tug of war that has characterized Cuban–US relations since the 19th century. Until the occurrence of this emotionally charged international event, few Americans were aware of the economic crisis that paralyzed the daily lives of Cuban citizens and provoked the collective uncertainty that led Elian, his mother, and scores of other Cubans to risk their lives traveling in a makeshift raft across the sea under the cover of night.

The year 1999 marked the beginning of the end of the Special Period, although indicators of economic despair remained quite evident. With the exception of the Spanish Embassy, buildings and streets were not lit at night. Billboards and walls were adorned
with the slogan “socialismo o muerte.” Electrical blackouts were both scheduled and random. Beautiful colonial buildings were crumbling and terribly unsafe. A state report released in 1995 indicated that twenty-five percent of the buildings in Havana were in marginal condition with twenty-three percent on the brink of collapse (Corbett, 2002). Clearly, the government did not have the resources to address infrastructure issues identified at that time and housing conditions continued to worsen. Gaping holes pierced the sidewalks and potholes provided obstacles to the few cars on the street. Early model Buicks and Plymouths were held together with ingenuity. Paper products were not available. US tourists were told to bring toilet paper with them and to kindly leave a few rolls in the hotels. Food rations provided to all families since the days of the revolution were decreased. Few stores were open. Not many, but a handful of Cubans begged on the street for soap. All Cubans stood on long lines to buy a loaf of bread and other staples. Restaurants enjoyed only the company of sparse tourist groups. Old Havana was dark, exhausted and falling down.

United States policy toward Cuba also had an impact on the daily experiences of Cubans prior to and during the nation’s period of economic crisis and assisted in shaping the circumstances that led to the surge of Cubans looking outside institutional systems for solutions to their problems. I traveled to Cuba for the first time as a member of a people-to-people exchange tour that provided organized opportunities to visit schools, family doctor clinics, hospitals, community farms and participation in cultural activities. At each

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iii socialism or death
scheduled and spontaneous event, Cuban state officials and ordinary citizens confronted my travel group about the role of the US embargo in the nation’s economic conditions.

The US–Cuba Embargo was implemented in 1962 during the time of the Cuban Missile Crisis. The Embargo forbids U.S. citizen travel and trade with Cuba. With the exception of a moratorium on the travel restriction from 1977–1982, various interpretations and forms of the initial legislation have remained as the keystone of US Cuban relations. During the height of Cuba’s Special Period two key pieces of legislation, The Cuban Democracy Act and the Cuba Liberty and Democracy Solidarity Act were passed by the US Congress. In an effort to tighten trade restrictions The Cuban Democracy Act, better known as the Torricelli Act, was signed into law in 1992. This legislation imposed severe penalties on subsidiaries of US companies located in countries that traded with Cuba and restricted remittances from American families to their relatives in Cuba. The Torricelli Act also allowed the President of the United States to provide assistance to Cuban dissidents (Martin, 2002).

The Torricelli Act laid the foundation for the Cuban Liberty and Democratic Solidarity Act, often referred to as the Helms-Burton Act of 1996. In addition to strengthening international sanctions already imposed upon Cuba, the Helms-Burton Act broadly expanded the scope of the embargo penalizing any foreign country that traded with the island nation and relinquished executive authority over all Cuban affairs to the US Congress (Corbett, 2002). When visiting family doctor clinics and hospitals in 1999 the impact of toughened US policy toward Cuba was obvious. Hospital dialysis units were reusing IV lines and the paper needed to record a patient’s heart activity during
electrocardiogram was not available. Family doctors requested donations of aspirin, bandages—supplies badly needed to meet basic health care needs but unavailable due to embargo trade restrictions. The remarks of one physician emphasized the paradox of Cuba’s health care system and the impact of externally imposed trade restrictions, “we have the knowledge, skill and organ availability to perform heart transplants but we do not have the medications to prevent infection and organ rejection.”

The primary objective of my Cuban visit in 1999 was to gain understanding of Cuba’s health care system, and disability services. I was also very interested in how Cuba’s socialist structure and distinct culture played a role in the formation and provision of rehabilitation services. Cuba’s model family doctor program, initiated in 1984, continued to provide free community-based preventive and primary medical services to families in their homes and the neighborhood clinic during the economic crisis despite lack of resources. The Latin American Medical School opened in 1996, trained medical students from Cuba, Latin America and the United States for future careers in underserved and impoverished communities. The Federation of Cuban Women, a non-governmental organization founded by Vilma Espin during the revolutionary years, supported the nation’s health initiatives taking on an active role in community health screenings and education. Cuba’s scope of medical practice: prevention, education, primary and secondary care, was on par with the level of services delivered in many industrialized countries. However, in my admittedly limited experience in Cuba in 1999, rehabilitation and disability services were not yet a priority of the health care or social systems. I observed very few individuals with disabilities in public spaces, and when I
asked about the notion of disability, responses were polite, but often dismissive of the topic.

During my subsequent visits, I sought out and began to learn about disability in Cuba. Each trip was humbling, confusing, and surprising. The best analogy to illustrate these experiences is perhaps the peeling of an onion. First, one needs to have a sense or a rudimentary plan of how to approach the onion. Usually the method does not go according to plan as one discovers that the beautifully fragile outer skin is the most difficult to remove. Abrupt, gross hand movements are replaced with subtle, refined peeling of the thinly protective layer that holds in its essence. It takes a while. Once the outer shell is removed, the translucent pearl layers are exposed. Now the onion displays its logical organization of structures that appear to be so easily dissected. But you are only to be fooled again, as the process to separate and dice the pieces becomes increasingly uncomfortable. Tears are usually involved. Questions of why one is engaged in this activity are raised. The core is finally revealed exposing the complexity of the object or phenomenon being examined.

When I returned to Cuba two years after my initial visit, observable and important economic and social changes had taken place. *Casa particulares* and *paladares*—self-employed guesthouses and restaurants—were in full operation and growing in number. Mercedes Benz sedans competed for taxi fares. Lights were still dimmed to comply with the state’s newly initiated energy conservation program, but blackouts were seldom. Old Havana was receiving a long overdue facelift thanks to international investments. Tour buses and foreign visitors populated the streets as Cubans donned colorful clothing and
costumes to entertain the new guests. The people on the street were less somber as chatter around sports and whispers about Fidel and the new economy were overheard while meandering through recently opened shops. The airport slogan that greeted us upon arrival had changed its message from “socialismo o muerte” to “patria es humanidad.”

Prior to my second visit I began to establish contact with individuals in the United States who were engaged in humanitarian or programmatic work relating to disability in Cuba. My networking led me to the Cuban Interest Section in Washington, DC. The Cuban Interest Section is housed in the old Swiss Embassy along Ambassador Row and serves as the unofficial embassy of the Cuban government. I met with the Cuban First Secretary for Health Programs to discuss the development of an academic exchange program in Cuba that would focus on the study of disability. At this time US policy permitted US–Cuba people-to-people and academic relationships. I was directed to contact a pediatric neurologist in Cardenas, Cuba who had recently opened a children’s rehabilitation center, the first facility of its kind in Cuba. With many twists and turns and the assistance of friends I was able to negotiate communication channels to make contact with Dr. Jorge Rodriquez, the director of the children’s center.

My visit in early 2002 provided general information about Cuba and the nation’s commitment to addressing the social issues revealed during the Special Period. During his presentation at the School of Social Work, Fidel Castro identified the priorities of the “social revolution”: improvement of the educational system by decreasing class size, reduction of truancy and dropout rates, identification of the needs of older adults living

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iv patriotism is humanity
alone, promotion of a comprehensive family culture that provides children with opportunities, and development of services needed by those with disability, particularly children and their families. President Castro estimated that in 2002 about 56,000 children “were suffering from some type of impairment… mental retardation, physical, behavioral… disabled due to accidents, during birth.” The solutions offered to address Cuba’s issues of disability included comprehensive family education, social work surveillance, and intervention and prevention of disability through genetic testing.

Toward the end of this visit I traveled to Cardenas to meet with Dr. Rodriguez to discuss the possibility of establishing an educational exchange program with his center. With the Cuban Interest Section functioning as a communication intermediary I received adequate information to draft a letter of intent to develop a collaborative program with El Centro de Rehabilitacion y Neurodesarrollo. A visit to the Center was scheduled on my travel itinerary and approved by el Instituto Cubano de Amistad con Los Pueblos (ICAP).

At the time of my initial visit Cardenas was a city of 96,000 inhabitants and home of a national ice cream plant. The sugar refinery was the town’s largest employer, and cecil, a plant used to make rope, was the primary export. Over twelve thousand of Cardenas’ adults worked in tourism in the neighboring beach community of Varadero. Children accounted for twenty-one percent of Cardenas’ population and the city boasted an infant mortality rate of 4.5 percent. While in Cardenas I visited a family doctor clinic,

\[\text{\footnotesize ICAP is a governmental agency that fosters people-to-people exchanges across cultures. It also serves as an intermediary in the approval and development of travel itineraries for international visitors.}\]
the provincial hospital, a primary school, a day care center for the well elderly and met with the president of the town. Children enrolled in the primary school eagerly presented the school’s new library—there were only a handful of books on the shelves. The factories visited during midday were not operating—the nation’s energy conservation initiative required a daily work stoppage. The provincial hospital had recently opened a new eight-bed intensive care unit—the beds had no sheets and there were no gowns for patients. A physician requested partnership with a US hospital for technological support and professional exchange. As I left the hospital, the peeling paint, broken stairs and cracks in the floors could not be hidden.

The next stop in Cardenas was El Centro de Rehabilitacion y Neurodesarrollo (El Centro). After searching for El Centro and negotiating narrow streets shared with horse drawn carriages, the driver stopped at a construction site surrounded by a barbed-wired fence. With the support of the German Communist Party El Centro was in the process of relocating from its storefront location into a refurbished rose-colored colonial building in the heart of town. My scheduled meeting took place on the construction site as blond haired men speaking German pounded nails and poured concrete. A young physician met me. We exchanged introductions, and I presented her with requested donations and a letter of intent to establish a relationship with the center. The visit was very short, and I left the site not knowing much of anything. Within a few weeks I received an email from Dr. Jorge Rodriguez, the Center’s director, inviting my university to develop a collaborative program with El Centro. I returned to Cardenas in 2003 with a group of occupational therapy students and faculty.
Between March 2003 and January 2007 I visited El Centro de Rehabilitacion y Neurodesarrollo six times. During these years Cuba continued to recover from its economic crisis. Beginning in 1999 the state introduced market initiatives that included the establishment of small businesses, collection of taxes and introduction of a dual dollar economy, with the United States dollar accepted as national currency. Revenues from augmented tourism; exportation of medical providers and alliances with Latin American neighbors and China replaced the withdrawal of economic support from the former Soviet Union and served to position Cuba as a potentially viable trade partner in the world economy.

This constellation of events and economic changes raised questions surrounding the stability and continuity of Cuba’s socialist structure and its allegiance to the core principles of the Cuban revolution, economic and social equality for all. Additional concerns were raised nationally and globally as Fidel Castro, Cuba’s president and commander-in-chief for 47 years, due to illness temporarily transferred his executive powers on July 31st, 2006 to his brother Raul. Raul Castro officially assumed the role of president and commander- in- chief of Cuba in February, 2008. The successful, peaceful and measured transfer of power, particularly after a period of profound economic and political uncertainty, underscored the nation’s strength and ability to transform as it maintained its structural, organizational and ideological tenets.

Although dramatic changes to Cuba’s economic and political landscape occurred during these Post-Special Period years, a formal academic exchange program between the Center and Thomas Jefferson University in Philadelphia was established. The trips took
on various forms including a study tour, educational and training workshops, program
development and pilot research. Program activities and visits were designed to meet the
needs of El Centro and comply with US policy toward travel in Cuba. Each visit
fostered new insights not only into the daily workings of this modest rehabilitation center,
but also the notable changes in the nation’s socio-cultural structure as Cuba recovered
from the devastation of the Special Period. My understanding of the contentious
relationship between US policy and Cuban development grew as the work I was doing in
Cuba was directly impacted by it.

In June of 2004 the Bush Administration imposed profound restrictions on travel
to Cuba, effectively eliminating most academic programs and reducing Cuban
Americans’ visits to Cuba to once every three years. When I arrived at Miami
International Airport with a group of students in June 2004, in addition to the usual
process of presenting documents signifying approval to travel to Cuba, my group was
asked to sign a form stating that we understood that due to the new travel restrictions set
to take place before our return date, we might not be permitted to re-enter the United
States. We returned without difficulty.

The June 2004 visit marked the beginning of my research interest in Cuba. I was
struck by the manner in which services were provided, the role that mothers of children
with disability played within the clinical environment, and the interactions between staff

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vi When the program was initiated in 2003, the US Treasury Office of Financial Assets
and Control permitted universities to obtain an academic license for travel to Cuba. In
June of 2004 the Bush Administration academic travel policy was tightened essentially
eliminating all academic licenses, restricting travel to 10 programs and professional
research.
and families. In collaboration with Dr. Rodriguez I developed a research agenda that would both be useful to El Centro and extend my understanding of the socio-cultural aspects of rehabilitation within this novel context. During subsequent visits in 2005 and 2006 I conducted pilot research\(^\text{vii}\) centering on programmatic needs assessment based on interviews with mothers and staff. The pilot research project produced more questions than answers. I became increasingly interested in the influence of the socio-cultural context in shaping attitudes toward disability, the delivery of services and the narratives of mothers as they care for their child with disability. Issues of the mothers’ individual agency within a socialist structure, the impact of limited material resources on the delivery of services and the diffusion of the ideals articulated by Fidel Castro in his call for a “second revolution, a social revolution,” to those with disability and their families, presented as relevant and germane to Cuba’s National Priority Disability program and enhanced understandings of cross-cultural aspects of disability. I then decided to focus my doctoral dissertation on the relationships between the experiences of mothers with children with disability in Cuba and the socio-cultural context in which they are located.

This study seeks to address the following questions:

- How do mothers of children with disability in Cardenas, Cuba make sense of their child’s disability in the present socio-cultural environment? How do mothers’ interpretations of their child’s disability reflect the structural conceptions and attitudes

\(^{\text{vii}}\) Pilot was conducted with approval of TJU Institutional Review Board and met OFAC travel requirements for professional research.
toward disability and inform the actions that they take in negotiating and promoting the inclusion of their child in social and educational environments?

- How do mothers’ interactions with institutional structures and personnel influence their utilization of services and engagement in rehabilitation services? How can the voices of mothers of children with disabilities in Cardenas, Cuba collaborate with the Center for Rehabilitation and Neurodevelopment to more effectively develop rehabilitation services, support the role of mothers in caregiving, and promote the social inclusion of children with disabilities?

- How do mothers of children with disability in Cardenas, Cuba view their role in affecting change in relation to location and participation of children with disability in social and educational environments? What actions can parents or caregivers of children with disability take to promote their child’s social participation?

The Research Context

For an American, conducting doctoral research in Cuba is both exotic and exceptionally challenging. It is a bureaucratic marathon and an extraordinary privilege. The governments of the United States of America and Cuba do not have a diplomatic relationship. Cuba is the only remaining country restricted to trading with the USA under the provocatively titled Trading with the Enemy Act of 1917. With the exception of a few US government approved conditions, such as Cuban-Americans visiting relatives, professionals conducting research, journalists and government officials, American citizens are banned from traveling to Cuba (US Department of State, 2009). So of course,
due to travel and trade restrictions in addition to American images of the charismatic Argentinean revolutionary, Che Guevara who became one of the great leaders of the Cuban revolution, and classic Chevrolets, Cuba is a mysterious and forbidden destination. Cuba also comes with a rebellious history, pronounced culture, unfamiliar institutional systems and different ways of being and living. Meeting the travel and research requirements of the US Treasury’s Office of Foreign Assets and Control (OFAC), approval of US Institutional Review Boards, approval of University Counsel and International Research Committees, approval from Cuba’s Ministry of Public Health and negotiation of visas is a long and arduous process. But along the way every person involved in the process was supportive, thorough and professional. After some minor delays due to schedules and holidays this research project was initiated in January 2009.

Returning to Cuba two years after my last visit in 2007 felt like returning to a home that had undergone renovations and been refurnished. Havana was bustling and buildings were restored and painted the cool colors of the Caribbean. The mix of faces and nationalities was surprising, new Chinese buses replaced the camel bus, English phrases punched the air everywhere and the unfamiliar sight of tourist shops gleamed in the sun. In Cardenas, the horse and buggies remain the main mode of transportation, but now a cinema café served cappuccino with sandwiches. Replacing the US dollar in the nation’s dual dollar economy is the Cuban convertible peso. The tourist shops, most restaurants and the cinema café only take the Cuban convertible peso, not the national peso, the currencies in which Cubans are paid. Twenty-six national pesos are the
equivalent to one convertible peso. Hence, most Cubans cannot enjoy a cappuccino at the cinema café or have a meal in Havana’s new beautiful spaces.

The talk on the streets of Havana, Cardenas and Varadero is no longer a whisper. Cubans are chattering loudly, but carefully. Invention, a Cuban trademark, is now more visible as professionals sell bootleg DVDs on government buses and young entrepreneurs work outside of typical arrangements. Alternative and creative schemes to acquire convertible pesos often fall outside the guidelines of the law and even with the apparent expression of these schemes it is difficult for the government to apply penalties due to the large-scale activity (Chavez, 2005). Events marking the history and achievements of the revolution are quieter and appear to receive less public attention than in the past. The “revolution” is in a state of flux.

This study is situated within Cuba’s Post-Special Period - in a nation in unending transition, hitting up against the midlife crisis of its revolution as it entered its fiftieth year. It looks at the experiences of the Cardenas mothers caring for their children with disabilities from multiple theoretical frameworks and varying levels of analysis. Attention is given to the agreement of outside perspectives and inside realities, the tensions of structure, culture and agency, and representations of collective identities and individual practices in the daily lives of those located in the world of disability. The Cuban health care system is a primary location in which individuals with disabilities, their families and caregivers are situated. Cuba’s innovative model of health care is presented in the following chapter to illustrate how structural conceptions of disability
and institutional health priorities collaborate to situate children with disabilities and their caregiving mothers within the larger social context.
CHAPTER 2
CUBA’S HEALTH CARE SYSTEM: DEVELOPMENT AND EVOLUTION

Cuba’s renowned health care system was the principal impetus for my initial visit to this Caribbean island. As an occupational therapist practicing in an underserved community in New York City, I became acutely aware of the limitations and gaps in the United States’ approach to chronic illness and disability. The hospital in which I worked was situated at the gateway to New York’s East Harlem community, a neighborhood known locally as Spanish Harlem. The families that I served, both in the hospital and in their homes, were poor, many barely educated and lacking the social or cultural capital to access services and negotiate the system. African-American families living in public housing projects, recent Mexican immigrants living undocumented in neighborhood tenements, and first-generation families from South America and the Caribbean islands were the heart of the community and the pulse of the hospital. Chronic illnesses and disability were familiar to these families as poverty and marginalization compromised their health. Rehabilitation therapists were unlikely to accept cases in impoverished neighborhoods, limited child care and funds for transportation resulted in missed health care appointments, and the rotation of physicians in public hospital clinics diminished the continuity of care and quality of services. The typical models of health care service delivery were ineffective in meeting the needs of the city’s most vulnerable population.
This experience led me to explore alternative, community-based approaches to rehabilitation. It was then that I became intrigued by Cuba’s particular and pioneering approach to health care.

Cuba’s internationally recognized health care model is both the product and symbol of the Cuban revolution. As such, during Cuba’s period of economic crisis in the 1990s the state assigned high priority to the maintenance of its health care services and population health status. Cuba’s distinctive health model has served the people and the state well, providing its citizens with free and equal access to available services and positioning the nation firmly in the global health care landscape. Cuba’s consistent high ranking in international measurements of health status has resulted in its moniker as a Third World country with First World health indicators (Feinsilver, 1993). Cuba’s commitment to assisting the health needs of less-developed countries is reflected in its greatest export, physicians. The medical diplomacy program initiated in 1963 continues to be an integral component of Cuba’s foreign relations as noted in the current significant presence of 30,000 Cuban physicians in over 70 countries in Central and South America, Africa and beyond (Feinsilver, 2008). When compared in 2002 to 20 other Latin American countries, Cuba earned the highest average ranking in eight health indicators and ranked the highest in infant mortality, mortality and percentage of malnourished children under the age of five years, percentage professional health assisted deliveries and life expectancy at birth (Brundenius, 2009). Moreover, Cuba’s health care successes and export of medical personnel positions the nation as an international medical expert, strengthening its role in international economic and social discourse.
Cuba’s social framework views health as directly related to the individual’s material environment and essential to high educational and occupational attainment (Feinsilver, 1993). Accordingly, Cuba’s health ideology views the health of the individual as representative of the wellness, strength and accomplishments of the state. Cuba’s medical diplomacy program not only functions as a proxy for the nation’s limited export of material resources, but also transports Cuba’s national health ideology internationally, serving as an important foreign policy tool that promotes global collaboration, trade and economic development. Cuba’s advances in medicine and its model of health care provide the nation with symbolic capital that in turn reinforces the legitimacy of the state and the tenets of Cuba’s socialist revolution. The significance of the health care system as the bedrock of the nation’s political legitimacy cannot be overstated. During three distinct points in Cuba’s history—the construction of the state’s socialist structure, the catastrophic economic crisis of the 1990s and the current Post-Special Period—the health care system has navigated the government through difficult and unchartered waters. Cuba’s introduction of socialized medicine was implemented during the earliest phase of the nation’s revolution, opening the door to the populace’s acceptance of broader socialist-based programs and policies. The state’s intentional maintenance of health services during its economic crisis fostered citizen allegiance as individuals suffered through food shortages and diminished material resources. At the present Post-Special Period the health care system offers an avenue to economic recovery and potential domestic sustainability with medical providers being its primary export. Appreciation of the ideology that grounds Cuba’s health care system is germane to
understanding not only the symbiotic relationship between the health of the Cuban government and the system it created, but also the role of the state and its institutions in shaping the health practices and behaviors of all Cubans, especially those with chronic illness and disability.

**Foundational Principles**

Cuba conceptualizes health as a fundamental human right. Thus the values that anchor Cuba’s health care services and policies are tightly aligned with the nation’s socialist ideology. Feinsilver (1993) identifies three key conceptions that guide Cuba’s health care and reflect principles of social justice, equality and the primacy of the collective. These notions are: 1) equal access for all to services, 2) an integrated biopsychosocial approach and 3) popular participation. The Cuban health care system is highly centralized with the government assuming fiscal and administrative responsibility for health care institutions, the workforce, identification of health priorities, delivery of services, health promotion and education activities. The first guiding principle of this system, equal access to all services, is couched in the state’s revolutionary commitment to eliminate class and educational differences through the provision of universal economic, geographical and cultural access to all available health care services. Cuba has succeeded in providing universal health care access to all its citizens.

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viii In Cuba the term cultural or culture is often used to signify class or educational status. In my experience, individuals are sometimes described as being of “high” or “low” culture suggesting that the individual is of low resources or educational background.
One of the earliest priorities of Cuba’s socialist revolution was to develop health care services in neglected rural areas of the country. This objective was secured through the state’s formation of the Rural Health Service in 1960. The state ensures economic access through the provision of free and comprehensive health services. Cubans enjoy unlimited access to primary care physicians, available surgical and rehabilitation services and existing biotechnology. Though access is guaranteed, availability of some basic medical procedures is not always predictable due to limitations in material resources. Economic accessibility is also constrained as individuals are required to pay for some medical expenses including medications, medical supplies, rehabilitation devices and mobility aids out of pocket (Speigel & Yassi, 2004). Cuba’s decision to exempt medical supplies and medications from the national payment plan emphasizes the system’s focus on primary care and raises questions surrounding full accessibility for older adults and those with chronic illness or disability.

Cuba considers collective access to health as the ideal mechanism by which to eliminate gaps in class and socioeconomic differences (Feinsilver, 1993). Furthermore, the state views the health of its children as an indicator of the country’s social development and future capacity as well as a marker of its achievement of universal access. As a result maternal and child health is the foundation and priority of the Cuban health system. In an effort to promote healthy pregnancies and reduce national rates of infant mortality and morbidity, women and young children receive considerable health surveillance by local family doctors with a woman typically receiving up to 15 prenatal visits during her pregnancy. One example that highlights the state’s heightened attention
to maternal and child health is found in the national standard that all pregnant women, not just women determined to be at risk, receive prenatal genetic testing and undergo ultrasound procedures to identify fetal congenital malformations. While this standard may exceed prenatal norms established by industrialized, high resource countries, the practice does support Cuba’s national health priority of healthy infants and low rates of infant mortality and morbidity. However, critiques of Cuba’s health care system point to this example as an indicator of Cuba’s over-utilization of services, inattention to cost effectiveness and question the impact of intensive health surveillance activities on individual health and social behaviors (Brotherton, 2005).

In contrast to many traditional models of Western medicine, Cuban health care emphasizes an integrated holistic approach that considers biological, psychological and social aspects of individual health. The individual’s physical and social environments are also taken into account. Cuba prides itself in viewing health care as a service centered on the development of human relationships between doctors and their patients. Health care in Cuba is not a business and patients are not clients. The Cuban physician is expected to be as attentive to an individual’s emotional well being, social support and housing situation as to physical and medical conditions. Toward that end, the family physician is charged with addressing the needs of his or her patients in a holistic manner incorporating health promotion, prevention, education and medical intervention into daily practice. The family doctor program, implemented in 1984, stresses the importance of the social environment in contributing to health. This national initiative locates physicians in the center of neighborhoods, inserting the medical clinic within the social fabric of the
The family doctor serves as the neighborhood guardian of health charged with the primary objective of preventing disease and reducing illness (Perez, 2008).

The family doctor model of service delivery indeed enhances accessibility to health care services and allows opportunities for an integrated approach to health. Services are readily available in the community, the doctor spends afternoons conducting home visits and all health, social and emotional needs are addressed by the physician. At the same time the model also turns private domains into public spheres as the physician is privy to most aspects of the patient’s and family’s personal lives. Similar to criticisms around universal access, Cuba’s integrated approach manifested in the family doctor program has raised concerns relating to the physician’s role in promoting the state’s agenda and controlling individual health choices and practices (Brotherton, 2005).

Popular participation, the third principle of Cuban health care, is linked to Cuba’s revolutionary values of collective involvement. This principle was conceived as providing the general populace with a role in health planning, administration and education (Feinsilver, 1993). Unlike established forms of collective health participation, such as community health extendersix popular in low resource areas, health participation in Cuba is generally expressed at an organizational level through activities of the Committees for the Defense of the Revolution,x the Federation of Cuban Women,xı and

ix Community health extenders are lay practitioners trained to provide basic health services in underserved and low resource communities

x Committee for the Defense of the Revolution-community neighborhood watch organization responsible for maintaining safety, health and well being of the community
the formation of topic-specific medical brigades. Popular participation and health education are interlinked as individuals and non-governmental organizations come together to promote health priorities identified by the state. The Committee for the Defense of the Revolution (CDR) is charged with supporting neighborhood health status and achievement of community health indicators. The Federation of Cuban Women (FMC) trains its members to educate and mobilize women around health issues. The Youth Pioneers receive instruction in basic first aid and also provide health education in support of the national health agenda.

The CDR and FMC were formed by the government in 1960 and are two of the most important mass organizations in Cuba (Perez, 2008). These organizations play pivotal roles in distributing health knowledge, surveying community health and supporting national health priorities. However, while these nongovernmental organizations seemingly satisfy the state’s objective of popular health participation, they in effect, may minimize individual health participation. Werner (2004b) suggests that the centralized role of the family doctor in health decision-making and the state’s opposition to relinquishing health authority to paraprofessional and community members also compromise full expression of popular participation. An interesting outcome of Cuba’s economic crisis in the 1990s is the increased local health care involvement and decision making as the state opened spaces for alternative forms of health care delivery due to its

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xi Federation of Cuban Women—nongovernment organization founded in 1960 to promote the rights and roles of women in the revolution and social structure

xii Youth Pioneers – Socialist youth brigade established in 1961
limitations in meeting some population health care needs\textsuperscript{xiii}. The Special Period provides an illustration of the responsiveness of Cuba’s institutional models and underscores the relationship between the health care system, social development and political legitimacy.

I am going to tell you something very interesting. Many of us spend our lives protesting- protesting for transportation, electricity, food or money because we don’t have enough. But when we have a need for a family member who is sick, a son, a daughter, grandson, when we go the hospitals, we see that we have it all, all that we need, all that I just said matters, doesn’t. (PP, Havana, July 1, 2004)

Cuba’s model of health care, with its attendant respected health indicators and dedicated physicians, serves as the definitive symbol of the success of the socialist revolution as an alternative to a capitalist based society. The revolution’s anti-imperialism message is tightly tied into the symbolism of the health care system through revolutionary language, health brigades, national recognition of local health achievements and the practices of its dedicated workers (Feinsilver, 1993). Warman (2001) contends that the Cuban health worker, specifically the physician, functions as the symbolic representation of the health care system and the revolution. Cuban doctors are expected to \textit{live} the revolution by being model citizens, sharing the frustrations of the strained economy equally with other citizens while practicing their profession 24-hours a day in a stressed health care environment. During Cuba’s economic crisis workers were granted government approval to seek alternative and innovative methods of income. Yet, health care workers were not permitted to engage in state sanctioned self-employment

\textsuperscript{xiii} An example is the state’s approval of herbal medicines during the Special Period in response to severe shortages of medications.
economic initiatives. Physicians were expected to continue their practice without necessary medical supplies, provide for their families without economic supplements and support the state’s economic recovery plan.

While in Cuba in 2004, I had the opportunity to meet a number of doctors who openly shared some of the hardships they experienced personally and professionally during the Special Period. Tales relating to the lack of medicines and basic supplies were common. One doctor in particular, eloquently and emotionally related his everyday life experiences in the course of the economic crisis. This prominent physician described taking turns with his wife, a psychiatrist, standing on long lines for several hours to purchase a loaf of bread. In their home toilet paper was padlocked in a closet so that a boarder would not abuse the privilege of having paper available. Household bar soap, obtained after hours of waiting in line, was unwrapped at home only to discover a block of wood covered with a thin veneer of soap.

Cuba’s health beliefs and priorities are communicated and maintained through a variety of mechanisms, including television, slogans, billboards, national pledges, political rallies and organizational structures. Billboards lining the countryside and city streets convey the principles of socialism and identify national health and educational objectives. Planned political rallies organized around historical moments of the revolution, joined with criticisms of United States policy toward Cuba, reinforce the tensions between capitalism and socialism as they herald the country’s health accomplishments. Cuba’s selection of social work students to head the disability health
brigade provides a potent example of conjoined symbolism linking health priorities with revolutionary practices.

Cuba’s exploration of disability was initiated as a National Priority Program in 2001. Social work students were charged with visiting every house in Cuba and documenting the number of individuals with disability residing in each household. The Social Work Brigade was developed in the established tradition of the Literacy Brigade formed in the post-revolutionary early 1960s. The concept of a brigade illustrates how ideology meets practice. Cuba’s Social Work Brigade and investigation of disability are described in a state produced video as follows:

A message of love and humanism constitutes the program of attention to disability and development of medical genetics that arrived on each part of the island of Cuba…. The memories of a revolution without precedent with the participation of more than 33,600 health professionals are realized in this documentary…. The objective of this profound study is to mitigate or minimize genetic, prenatal and birth related problems…. On May 1, 2003,\textsuperscript{xiv} at Revolutionary Plaza the testimonies of some of the participants and families that benefited from the program will offer the magnitude of their experience of converting their dreams into reality, to obtain a society more just and humane. (Por La Vida, Estudio de las personas con retraso mental y otra discapacidades, Video produced in Cuba, 2004)

The Cuban state considers health indicators to be indicative of government efficiency and representative of the success of its socialist structure. The state’s recognition of health care as the prevailing symbol of the revolution and the political power gained in maintaining health care services became increasingly evident during the

\textsuperscript{xiv} May 1\textsuperscript{st} is May Day internationally recognized.
economic crisis of the 1990s (Barberia & Nemser, 2002). Cuba’s general ability to sustain the nation’s health status, particularly in light of the augmented trade restrictions imposed by the US Democracy Act,\textsuperscript{xv} fortified Cuba’s commitment to socialism and legitimized its admonishment of imperialistic capitalism as the country tried out market based recovery initiatives.

The significance of the state’s ability to maintain the nation’s health status during its economic crisis calls for considerable attention. What also needs to be examined and understood is that, prior to the Special Period, Cuba consistently paid close attention to the state of its health care system, responded to population needs and made adjustments to care models, practitioner training and health priorities. Cuba’s ongoing post-revolution evolution of health services can be viewed as reflexive of global contextual influences and the dynamic nature of its socialist model. Cuba’s consistent response to population health needs and priorities was as critical to the government’s political legitimacy prior to the Special Period as was its sustainability during the economic crisis of the 1990s.

\textbf{Cuba’s Revolutionary Health Care System: A Work in Progress}

Cuba’s post-revolutionary health care system evolved in response to population health needs and national inequitable distribution of health care services. In part, the genesis of the country’s medical model grew out of the revolutionaries’ witnessing of

\textsuperscript{xv} The Cuban Liberty and Democratic Solidarity Act of 1996 Pub. L. 104-14 more commonly known as the Helms-Burton Act strengthens the United States embargo against Cuba by extending the application of the initial embargo to foreign nations that trade with Cuba.
extreme poverty and scarcity of health care services in Cuba’s eastern rural provinces. The revolutionaries responded to these needs by providing free health care to the people in the areas that they controlled. Che Guevara, who had been a physician in Argentina before becoming an instrumental figure in the Cuban revolution, crafted the new government’s socialist health care model in 1960. This model was initiated in the rural sections of Cuba and led to the formation of the Rural Health Service. The Rural Health Service required that all Cuban medical students perform one year of service in rural areas upon graduation. This initiative set the foundation for universal geographical access, thereby bridging the gap between rural and urban service delivery (Feinsilver, 1993).

Throughout the early 1960s post-revolutionary health care efforts were dedicated to structural organization (refer to Table 2.1). The Ministry of Public Health replaced the old Ministry of Health and Welfare. The People’s Health Commission was created to coordinate interactions between community organizations, health institutions and the workforce. The Committees for the Defense of the Revolution and The Federation of Cuban Women were formed to support health initiatives and mobilize individuals for health related tasks. National campaigns were organized to reduce illiteracy and disease as new health care facilities were built (Perez, 2008). Health centers became polyclinics dividing the population into regional health sectors overseeing not only the provision of health services but also adherence to health policy and achievement of state defined health outcomes. Cuba’s first medical brigade was sent to Algeria establishing international medical diplomacy as a mainstay in Cuba’s health framework.
As these structural changes took hold, tensions between the state and the medical community grew. Ideological differences surrounding health care delivery increased, resulting in almost half of the physician population emigrating to the United States and other countries. During the latter half of the 1960s the government achieved full control of the national health care system, affirmed its commitment to regionalized and population based medical services, and pledged to eliminate differences in health care provision.

The 1970s brought focused attention and commitment to international health and medical diplomacy, positioning of Cuba as a world medical power. In 1976 Cuba’s health care ideology and mission were documented in the Cuban constitution. The text reinforces guiding principles of equal access, an integrated approach and popular participation:

Everyone has the right to health protection and care. The state guarantees this right by providing free medical and hospital care by the means of the installations of the rural medical service network, polyclinics, hospitals, preventative and specialized treatment centers; by providing free dental care; by promoting the health publicity campaigns, health education, regular medical examinations, general vaccinations and other measures to prevent the outbreak of disease. All the population cooperates in these activities and plans through the social and mass organizations. —Article 50, 1992 Cuban Constitution (Constitution of the Cuban Republic, 1992)

Significant and transforming changes to Cuba’s model and delivery of health services occurred during the 1980s when Cuba introduced the Family Doctor Program. This program was designed to firmly plant health care services in the community. A doctor and nurse team is assigned to care for approximately 150 families within a defined
number of neighborhood blocks. This team is charged with the investigation, monitoring and maintenance of the health of all individuals, from the cradle to the grave, within their assigned neighborhood region. The medical team is expected to assess health status, detect health risk factors, prevent and cure disease, promote physical fitness and provide rehabilitation services. Patients are seen by the medical team in a three-room dispensary and in their homes. All physicians and nurses live in the neighborhood they serve in order to provide continuous care and be immersed in the social environments in which their patients function (Feinsilver, 1993). The family doctor program became the signature of the Cuban health care system and ultimately the key to Cuba’s economic development and enhanced foreign relations.

On the heels of the implementation of the family doctor program the nation’s leading trade partner, the Soviet Union began to decrease material and financial support to Cuba totally eliminating all forms of assistance by 1989. Shortages of medicines, medical supplies and energy resources resulted in Cuba’s exploration of new health care methods and identification of new resource avenues. In the mid 1990s Cuba began to integrate alternative and complementary health procedures into traditional medical practice. Research and development efforts were directed to biotechnology and pharmaceuticals as Cuba sought to produce its own resources. Medical diplomacy and health tourism were identified as the most potential sources for economic development. Cuba’s Special Period had a significant impact on the country’s health care system, collective well being and individual health. Understanding the impact of Cuba’s economic crisis and its relationship to individual health and current health priorities is
essential to this study’s examination of disability and is discussed in greater depth later in this chapter.

As Cuba began to recover from its economic crisis in 1996, the health care focus switched to larger societal problems uncovered during the Special Period. These priorities included frail older adults living alone, youth criminality, teenage pregnancy, families of low culture and individuals with disabilities (personal communication, director of Center for Psychological and Sociological Research, 2002; public presentation, Fidel Castro, 2004). In addition to the identification of domestic issues requiring attention, the state also acknowledged the importance of developing international relations and trade agreements now vital to the country due to the loss of Soviet Union support. The export of human capital—that being Cuban medical doctors—along with general and health tourism were identified as the keystones of Cuba’s Special Period economic development plan.

Drawing upon the market value of Cuba’s medical workforce and training curriculum, The Latin American Medical School was established in 1999. The aim of this medical school is to train students from poor Latin American and African countries in medicine. Students receive full scholarships to attend the program with the commitment to return to their native counties and work for at least 5 years in poor communities. This program is also made available to American students from poor cities (Reed, 2008). During my visit to this school in 2002, four students from the United States were in attendance. In 2006 over 24,000 international students were enrolled in the Latin American Medical School. Eighty-five of the students were from the United States of America (Feinsilver, 2008).
As Cuba moved into the 21st-century the nation was able to convert the symbolic capital gained from the Latin American Medical School into material capital. Funding from nongovernmental agencies was channeled to Cuba to expand its training of physicians from Third World countries. This funding provided Cuba with some economic gain, though perhaps more noteworthy is the role of the Latin American Medical School in extending Cuba’s health ideology and the scope of its medical diplomacy program beyond expectations. The opening of the Latin American Medical School coupled with national difficulties identified during the Special Period ushered in new initiatives aimed at addressing social conditions and the needs of those with chronic illness and disability.

Cuba’s first School for Social Work was opened in 2000 to address the health and social problems uncovered during the Special Period. The students who attend this school are trained to provide a wide range of services including tutoring children, working with families of low culture, identifying youth engaging in criminal activities, supporting health promotion and documenting the number of individuals living in Cuba with disability (Castro, Public presentation at the School of Social Work, February 2002). In 2001 disability was identified as a National Priority Program and studies were conducted to determine the scope of individuals with disabilities and their needs. Although regional rehabilitation services were available at the time in Cuba, it is my understanding through conversations with health providers, individuals with disabilities and representatives of the government and nongovernmental organizations that the state’s attention to the needs of those with disability through the National Priority Program was unprecedented.
So now they know the number of people with disability. The first meeting they had with Fidel, they kept Fidel posted about the quantity, the big number of disabled people that live in that town; and he notices that the number of disabled people was high. So last year, 2003, a national investigation of disabilities was carried out on the national level in municipalities of the country. The community doctors, psychologist, geneticists and some other specialists participated. So when this investigation brought about the idea of creating a program to take care of the disabled people, that’s why in all of the clinics they are building a room for rehabilitation people. (J. Rodriguez, personal communication, 2004)

Findings from the National Disability Report in 2003 indicated the need for more support for the families of individuals with disability—particularly funding from the government for the development of additional rehabilitation centers, implementation and enhancement of prenatal genetic testing and expanded research on the families of the disabled (personal communication, J. Rodriguez, 1/14/09).

While Cuba attended to the development of social programs and investigated the needs of individuals with disabilities, it also significantly expanded its medical diplomacy program and economic positioning during the first decade of the 21st century. Feinsilver (2006) reports that in 2005 Cuba provided medical services or support in 68 countries across the globe. During that year over 10,000 students from developing countries were on scholarship studying medicine in Cuba at the Latin American Medical School and other institutions. Jose Ramon Baluager, Cuba’s Public Health Minister, reported to Prensa Latina (2007) that since 1963 100,000 Cuban health professionals have provided medical care worldwide. These professionals have offered 300 million medical consultations, performed two million surgeries and saved about one million lives in emergency situations.
A strong indicator of Cuba’s success in couching medical diplomacy as the mainstay of its economic development is seen in its relationship with Venezuela and Bolivia. The Bolivarian Alternative for the Americas (ALBA), a multilateral agreement to unite Latin America in social justice oriented trade and aid, provides the structure for Cuba’s medical export initiative. Under the guidelines of ALBA Cuba has supplied Venezuela with over 30,000 physicians in exchange for preferential trade, oil and investment in Cuba (Feinsilver, 2006; Monreal, 2006). Cuba has exported not only physicians to Venezuela but also its model of comprehensive, integrated health care. Venezuela’s Barrio Adentroxvi program and Operation Miraclexvii (refer to Table 2.1) are staffed by Cuban doctors, emphasize a humanistic approach to medicine and provide free 24-hour care.

Cuba is once again able to convert symbolic valuexviii into economic gain though now on a much larger scale as medical diplomacy has garnered bilateral and multilateral aid in the form of trade or funding from host countriesxix and nongovernmental organizations such as the World Health Organization, the Pan American Health Organization and 85 other organizations (Feinsilver, 2006). The growth of Cuba’s

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xvi Barrio Adentro—Inside the Neighborhood—Venezuela’s renaming of Cuba’s family doctor program

xvii Cuban medical brigade providing eye surgeries

xviii Question the use of the term symbolic capital—the term capital—in opposition to sociologist ideology.

xix Cuba does provide many services to host countries for no compensation or below the market value.
medical diplomacy program has strengthened Cuba’s humanitarian image, economic position and global influence. Feinsilver contends that it is Cuba’s medical diplomacy program rather than its socialist ideology that is a threat to other nations of the world, as Cuba’s doctors provide a serious challenge to long held ideals of capitalist-based values about the structure and functioning of the health systems and medical professions.

Table 2.1

*Evolution of Cuban health care system*

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1956–1959</td>
<td>Cuban Revolution</td>
</tr>
<tr>
<td></td>
<td>Revolutionaries provide free medical care to peasants in rural areas under their control.</td>
</tr>
<tr>
<td>1959</td>
<td>Fidel Castro assumes presidential power.</td>
</tr>
<tr>
<td>1960</td>
<td>Rural Health Service established requiring all medical students to serve one year in rural areas.</td>
</tr>
<tr>
<td>1962</td>
<td>First mass vaccination campaign with assistance of local CDRs</td>
</tr>
<tr>
<td>1963</td>
<td>First medical mission to Algeria</td>
</tr>
<tr>
<td>1964</td>
<td>Health centers transformed to polyclinics.</td>
</tr>
<tr>
<td>1965</td>
<td>Medical school graduates denounce private medical practice.</td>
</tr>
<tr>
<td></td>
<td>Medical school graduates denounce private medical practice.</td>
</tr>
<tr>
<td></td>
<td>Medical school graduates denounce private medical practice.</td>
</tr>
<tr>
<td>1967</td>
<td>Last private medical clinic taken over by the government to form public health system and form socialized medical system.</td>
</tr>
</tbody>
</table>

*(continued)*
<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1968</td>
<td>Medical school teaching is decentralized and committed to developing curricula based on regional needs.</td>
</tr>
<tr>
<td>1975</td>
<td>Enhanced commitment to medical diplomacy in Africa</td>
</tr>
<tr>
<td></td>
<td>Re-establishment of the Institute of Tropical Medicine in order to meet the needs of medical mission in less developed countries</td>
</tr>
<tr>
<td>1980s</td>
<td>Decentralization of health care administration to monitor efficiency</td>
</tr>
<tr>
<td>1984</td>
<td>Creation of family doctor program</td>
</tr>
<tr>
<td></td>
<td>Doctor and nurse assigned to every block in Cuba.</td>
</tr>
<tr>
<td></td>
<td>Medical curriculum revised to reflect needs of family doctor program.</td>
</tr>
<tr>
<td></td>
<td>All medical students required to perform a residency in general medicine.</td>
</tr>
<tr>
<td>1989</td>
<td>Soviet Union withdraws material support from Cuba.</td>
</tr>
<tr>
<td>1990s</td>
<td>Economic crisis leads to severe shortages of medicines, medical supplies and replacement of medical equipment.</td>
</tr>
<tr>
<td></td>
<td>Malnutrition and vitamin deficiency</td>
</tr>
<tr>
<td></td>
<td>Increased use of complementary medicines</td>
</tr>
<tr>
<td></td>
<td>Enhancement of biomedical, pharmaceutical and biotechnology research</td>
</tr>
<tr>
<td>1996</td>
<td>Helms-Burton Act passed by US Congress.</td>
</tr>
<tr>
<td></td>
<td>Cuba promotes health tourism in response to economic crisis.</td>
</tr>
<tr>
<td>1999</td>
<td>Latin American Medical School founded.</td>
</tr>
<tr>
<td>2000</td>
<td>School of Social Work founded.</td>
</tr>
<tr>
<td>Table 2.1</td>
<td>(continued)</td>
</tr>
<tr>
<td>2001</td>
<td>Disability identified as National Priority Program.</td>
</tr>
<tr>
<td>2002–2003</td>
<td>Enhancement of medical missions to Latin America</td>
</tr>
</tbody>
</table>
Projecto Milagros, Neighborhood Doctor

Implementation of National Disability Investigation

2006  23,382 Cuban doctors provided services through Barrio Adentro I, primary health care program.

Barrio Adentro II implemented providing physical therapy and rehabilitation, applying 1.6 million rehab treatments.

Established medical cooperation program with Bolivia (Feinsilver, 2006).

See Appendix A for timeline of US–Cuba Relations

**Structural Organization of the Cuban Health Care System**

Cuba’s health care system, centered on the family doctor model implemented in 1984, has undergone a series of changes since its revolutionary inception in 1960. However, key features of the system, namely 1) a centralized top-down managerial approach, 2) primacy of the physician in provision of all services and decision making and 3) focus on population health indicators have remained (Feinsilver, 1993). Cuba’s dedication to humanitarianism, doctor–patient relationships, the social environment and the role of the collective in supporting health initiatives still remain intact. The government remains committed to free universal access for all citizens, an integrated approach and popular participation, though adherence to these principles have been affected by residual social and economic disparity manifested during Cuba’s economic crisis. The Special Period had an impact not only on Cuba’s health and social standing but also on the organization of the health care system.
The Cuban government holds all administrative, policy, fiduciary and educational responsibility for the health care system, its workforce and the individuals the system serves. The state organizes and manages these responsibilities through hierarchical state structures headed by the National Popular Power Assembly, the Council of the State and the Council of Ministers. The Ministry of Public Health functions as the complementary institution to the state’s authoritarian health care bodies, overseeing implementation and adherence to all health policies, delivery procedures and distribution of material and human resources. Governmental and health system level organizations are then divided at provincial, municipal and local levels with services organized into three tiers: primary care, hospitals, and specialized care including biotechnology institutes and research settings (Feinsilver, 1993; Perez, 2008; Speigel & Yassi, 2004; see Figure 2.1).
Regionalization of Cuba’s health care system permits equal access to health care, decreases redundancy of services and supports the government’s central control over the
system. The family doctor is the point of entry for all citizens who wish to access Cuban health care services. As previously presented primary care is provided in neighborhood consultarios, three-room health dispensaries typically adjacent to the community doctor and nurse’s homes. The primary focus of the consultarios is to prevent disease, promote health and administer clinical intervention. After morning office hours the family doctor conducts community home visits to patients with acute conditions, chronic illness or with rehabilitation needs. Family doctor consultations address an estimated 80 percent of the population’s health problems (Dresang, Brebrick, Murray, Shallue, & Sullivan-Vedder, 2005).

I had the opportunity to visit a handful of family doctor consultarios during my visits to Cuba between 1999 and 2007. Indeed each doctor that I met lived in the neighborhood and offered services in a three-room clinic. The clinics were open and airy with a strong sense of community as members wandered in for conversation between visits, comfortably chatting with the doctor with their young children or family pets in tow. The lack of medical supplies and equipment was evident during tours of each community clinic. Basic supplies such as alcohol pads, bandages, gauze, syringes, cotton balls, and surgical tape were not available and donations from United States hospitals were often solicited. In spite of the lack of material resources each physician voiced pride in his work, easily citing the community health indicators and initiatives and emphasizing Cuba’s philosophy of humanism in health care.

The waiting areas of the consultarios boast bulletin boards with the community health accomplishments, awards from the national government and are populated with
health education information. One of the consultarios I visited in Cardenas addresses the needs of children and adults living in a six-block radius. The doctor at this clinic and his nurse provide services to 773 people who are categorized as being healthy, at risk or with problems. The primary health issues confronted by this community are reflective of the national health priorities: promoting infant wellness and addressing the needs of the increasing elderly population with chronic illness. As Cardenas is one of the only three provinces in Cuba that has a rehabilitation center for children, those that are identified by the family doctor as having neurological problems are referred to El Centro for consultation. All other cases that are beyond the scope of the family doctor are referred to the local polyclinic for consultation or diagnostic testing.

An interdisciplinary medical team offering specialty care in pediatrics, neurology, dermatology, psychiatry, surgery, dentistry, complementary and alternative medicines, physical therapy and other medical specialties staffs the polyclinic. Each polyclinic serves 30–40 family doctor clinics throughout the municipality, maintaining a close relationship with the family doctor throughout the course of treatment at the polyclinic (Dresang et al., 2005; Feinsilver, 1993; Speigel & Yassi, 2004). The polyclinic environment has an air of professionalism and staff interactions with patients retain a community, personal attitude. Similar to the consultarios, the polyclinics are in need of material resources, but are much better stocked than the neighborhood clinics due to recent trade agreements with China and European countries. A polyclinic that I visited in Cardenas in 2005 was newly equipped with exercise equipment, acupuncture supplies, a

xx Santa Clara and Havana provinces also provide rehabilitation services for children.
traction device and rehabilitation materials. Ultrasound and endoscopy are now also available in the polyclinics (Cooper, Kennelly & Orduñez-Garcia, 2006). It is my impression from this visit that additional medical services are now moving from the level of municipal hospital to the polyclinics, establishing the polyclinics as the epicenter for secondary care and in turn increasing the population’s access to more specialized intervention. Over the next few years more than 400 polyclinics are to be renovated and fitted with contemporary medical equipment. Additionally the state is charting a course of health care decentralization as it restructures health care delivery into sectors staffed by a basic health care team. The polyclinics will also offer enhanced on-site medical training (De Vos, De Ceukelaire, Bonet, & Van der Stuyft, 2008).

The municipal hospitals in Cuba remain the primary site for secondary care offering general medical and surgical intervention. The municipal hospital offers diagnostic testing and other procedures that are standard practice in American community hospitals. Advanced medical procedures including dialysis also take place at the municipal hospital. Medical and pediatric intensive care units were available in the hospital I visited in Cardenas. At the time of my visit in 2004 the municipal hospitals were limited by a shortage of material resources including basic infection control supplies, hospital bed linens, IV lines, and sterile dressings. Similar to many buildings throughout Cuba, the hospital infrastructure was in desperate need of repair due to lack of attention or acquisition of materials required for building maintenance during post-revolutionary years. I observed collapsing stairways, gaps in flooring, peeling paint, and makeshift walls. Cuba’s recent identification of general and health tourism as the main
stimulus for economic development has led to a spurt of construction and enhanced attention to the integrity of public spaces. Perhaps these improvement efforts have extended or will extend to the municipal hospitals. The provincial hospitals providing tertiary care and the national hospitals round out the Cuban health care system. The national hospitals provide super-specialty care and are organized according to area of specialization such as the National Rehabilitation Hospital and the Psychiatric Hospital. As reported by Cooper and others (2006), Cuba’s 48 municipal hospitals have undergone modernization as they are now equipped with interventional cardiology and magnetic resonance imaging (MRI) availability.

The organizational structure of the Cuban health care system has also been responsive to population needs. Expansion of the polyclinics throughout the country in combination with adoption of a more interdisciplinary approach reflects the state’s attention to the changing national health profile. Additionally, the polyclinics have taken on a role in capacity building and monitoring health service quality in the larger community health related institutions (Reed, 2008). Many of these changes can be attributed to Cuba’s success in primary care services that increased life expectancy. Yet the nation’s economic crisis also played a significant part in new patterns of chronic disease and disability.

**The Impact of Cuba’s Special Period on Health**

Cuba’s Special Period clearly had an effect on the nation’s health care system and population health status. During the economic crisis the state paid close attention to the
integrity of the health care system recognizing the importance of the system as a symbolic representation of the health of the polity. The government made efforts to maintain public health indicators, particularly mortality and morbidity rates, uninterrupted health care services and promotion of the health of pregnant women and young children. Although Cuba was able to maintain and even improve basic health indicators during this time, severe shortages of medicines and medical supplies compromised the quality of the health care system (Brotherton, 2005; Speigel & Yassi, 2004).

As previously mentioned, Cuba’s health care challenges during the economic crisis can be attributed to a combination of factors including poor nutrition, inadequate hygiene and limited energy resources. The potency of these factors was compounded by the 1992 passage of the US Democracy Act that strengthened trade restrictions stipulated by the US embargo forbidding American companies from selling goods to Cuba. The previously mentioned, more restrictive Cuban Democracy Act prohibited international subsidiaries of US companies from selling medicine or food to Cuba and prevented ships that berth in Cuba from docking at US ports for six months after their stay at the island. For all intents and purposes this act cut Cuba off from any potential trade of food and medical products produced outside of the United States. Products from other countries cost Cuba approximately 30 percent more than those purchased from the US, and shipping costs were 50-400 percent higher (Garfield & Santana, 1997).

Werner (2004a) reports that during the Special Period the average Cuban’s caloric intake dropped by one third. Irregular food consumption, Vitamin A and B deficiencies
and replacement of unavailable food sources with excessive sugar consumption are associated with Cuba’s neuropathy epidemic observed between 1992 and 1993 (Roman, 1995). Scarcity of soap and other hygiene products; poor sanitary conditions; deteriorating social situations and medical facilities resulted in outbreaks of scabies, increased maternal and child death caused by respiratory and diarrheal disease, and rising tuberculosis rates. The proportion of low birth weight infants rose 23 percent from 1989 to 1993. Inadequate weight gain during pregnancy rose 18 percent with more than 50 percent of pregnant women presenting with anemia in 1991 (Garfield & Santana, 1997).

The malnutrition and epidemic of neurological disease in Cuba during the peak years of the Special Period were awarded only limited discussion or critique in academic writings and popular press reports. Capitalizing on the country’s social cohesion and past practices of medical brigades, Cuba was able to recover from the initial medical crisis within two years (Cooper et al., 2006), but the long-lasting effects of this health and economic crisis are subtle, yet present. Cuba’s neuropathy epidemic was the most significant and largest neurological epidemic of the 20th century, affecting over 50,000 Cuban citizens (Roman, 1995; Garfield & Santana, 1997). Individuals presented with a host of neurological symptoms including hearing loss, low vision, difficulty walking, loss of sensation and progressive muscle weakness. Increased rates of low birth weight infants were reported in 1992–1993. Cuba’s health indicators, over time, demonstrate the nation’s health recovery in relation to mortality rates, but do not capture the full scope of subsequent morbidity due to material shortages. The table inserted below (Table 2.2) presents national health indicators at key points in Cuba’s economic crisis and recovery:
1996, 1999 and 2002. As noted in the table, during the final year of the Special Period, 1999, increased rates in accidents, cardiovascular disease and diabetes were documented. Though these reported statistics are not comprehensive, nor can the quality of this information be evaluated in comparison to other data sources, xxi the state’s observation of these trends is evident in its national health priority shift in 2002 towards disability and older adults. The long-term consequences of low-birth weight infants and increased rates of neurological and medical conditions during the economic crisis are now evident in children and adults requiring disability services and social support. However, with the exception of the National Disability investigation conducted in 2002, national health disability statistics, to my knowledge, are not included in annual health indicator reports. Limitations in disability statistical information compromises the state’s health care system’s ability to construct a framework to understand the phenomenon of disability and to craft appropriate and relevant disability services.

xxi It is my understanding that health data is collected, evaluated and disseminated only by the state, thus comparison of data to information collected by private or independent organizations is not available. The data represented in Table 2.2 was accessed through INFOMED, the national database and resource for health information in Cuba. Cuba reports these health indicators to Pan American Health Organization.
Table 2.2

*Cuba General Health Indicators*

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<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population</td>
<td>11,005,866</td>
<td>11,142,000</td>
<td>11,250,979</td>
<td>11,257,105</td>
<td>11,239,128</td>
</tr>
<tr>
<td>Total Births</td>
<td>140,276</td>
<td>150,785</td>
<td>141,276</td>
<td>120,716</td>
<td>112,472</td>
</tr>
<tr>
<td>General Rate of Fertility (per 1000 women from ages 15–49)</td>
<td>46.7</td>
<td>49.2</td>
<td>46.7</td>
<td>39.9</td>
<td>37.3</td>
</tr>
<tr>
<td>Global Rate of fertility (children per woman)</td>
<td>1.49</td>
<td>1.60</td>
<td>1.63</td>
<td>1.46</td>
<td>1.5</td>
</tr>
<tr>
<td>Infant Mortality Rate (for every 1000 born alive)</td>
<td>7.9</td>
<td>6.4</td>
<td>6.5</td>
<td>6.2</td>
<td>5.3</td>
</tr>
<tr>
<td>Mortality Rate in minor (less than 5 year of age for every 1000 born alive) (TMM5)</td>
<td>10.7</td>
<td>8.3</td>
<td>8.1</td>
<td>8.0</td>
<td>6.7</td>
</tr>
<tr>
<td>Perinatal Mortality</td>
<td>12.4</td>
<td>12.2</td>
<td>16.6</td>
<td>15.5</td>
<td>14.4</td>
</tr>
<tr>
<td>Rate of low birth weight infants</td>
<td>7.3</td>
<td>6.5</td>
<td>5.9</td>
<td>5.4</td>
<td>5.4</td>
</tr>
</tbody>
</table>


xxii Health statistics prior to 1996 were not available in Cuba’s national health statistics database
The Special Period not only influenced changes in the population’s health status it also compromised health care resources and service delivery. In her interviews with Cuban patients and practitioners, Tania Jenkins (2008) found that informants identified the lack of medication, shortage of medical supplies and the shortage of medical personnel as the most significant test to the nation’s health care system. Hoarding of medication and inflated cost of drugs resulted in Cubans buying medications at distant international pharmacies with US dollars. Limited availability of diagnostic supplies such as x-ray films significantly affected institutions’ ability to perform diagnostic and intervention procedures. The combination of physicians leaving their positions for opportunities in tourism and the “commodification of doctors for export” (Jenkins, 2008, p. 1391) led to shorter patient visits, longer waiting times, exhausted physicians and unsanctioned visits to dollar doctors.xxiii

Another understated, yet significant outcome of the Special Period is seen in the rise of informal health networks among citizens to meet their own health needs. Cuba’s limited supply of medicines, food and health supplies led individuals to maximize their health literacy obtained through years of health education bombardment. Cubans sought their own solutions to health problems through complementary and alternative approaches, procured self-prescribed medications from relatives abroad and became consumers of their own health services. Individuals became active in filling in the health care gaps created by the state and rationalized their actions as being in line with Cuba’s health ideology of access for all, to all (Brotherton, 2005). These less pronounced

xxiii Payment of US or Convertible Cuban pesos dollars for a visit
consequences of the Special Period have also drawn attention to individuals with disabilities, enhanced popular participation at the individual level and opened spaces for health practitioners who are not medical doctors.

David Werner (2004b) provides an example that lends some support to this analysis. Werner states that prior to the Special Period, Handicap International approached Cuba to implement a pilot Community Based Rehabilitation (CBR) program. Although CBR models are prevalent in developing countries, Cuba declined the invitation citing CBR as a second-rate method for delivering rehabilitation services to individuals with disabilities. When approached again in 2001 Cuba accepted the offer. Werner posits that this shift in thinking can in part be credited to the constraints of the economic crisis and accompanying embargo. He suggests that “Cuba has been rediscovering the importance of giving more responsibility to families and communities in meeting their own needs” (Werner, 2004b, p. 1). Brotherton (2008) notes that since the Special Period, Cubans armed with a high level of medical literacy have been seeking their own solutions to health care system gaps and obstacles. He further contends that during the economic crisis the state created “spaces of informality” as economic strategies to promote individual assets that in turn would contribute to the informal market and reinforce the functioning of Cuba’s institutional structures, particularly health care. Although an organizational structure that supports increased individual health

xxiv spaces of informality—opportunities to participate in self employment, access to US dollars through remittances

xxv Essentially the state would provide basic universal care, and resources not available are obtained in the informal market—linking the two systems.
participation and decision-making may be a future component of Cuba’s evolving health care system, it may be a function of economic necessity rather than an extension of individual agency.

**Cuba’s Evolving Health Care System: Global Health and Tertiary Care**

Cuba’s health care model is internationally renowned and has withstood the test of economic collapse. Cuba has been very effective in providing public access to health care services, culturally, geographically and economically. The nation has developed a sustainable biomedical research infrastructure, controlled infectious diseases and educated a skilled medical workforce (Cooper et al., 2006). Cuba’s family doctor model and medical diplomacy program provide the nation with economic capital and global influence. At the same time the nation’s health care system is at a pivotal juncture in its evolution as it struggles with strained material resources and limitations in meeting the needs of a population with chronic illness and disability.

The family doctor program is the hallmark of the Cuban health care system. The program is lauded for its integrated approach, accessibility and community orientation. Critics of the program comment on the tendency or intention of the program in fostering health dependency, promoting overutilization of services, limiting physicians’ professional development and in turn compromising competence in managing complex cases. The scope of the family doctor’s role is evaluated as being too broad, as the doctor is assigned the responsibility to promote social cohesion, provide exercise and rehabilitation services, maintain statistics and promote environmental hygiene in addition
to other medical tasks. Family doctor service delivery methods such as medical visits in people’s homes, intensive health surveillance activities and doctor autonomy in health decision making raises questions surrounding issues of social control afforded by this model of health care delivery (Brotherton, 2005; Feinsilver, 1993).

The state holds full authority for medical training, deciding medical school admissions, number of doctors produced, curricula and assignment placement. The state’s tight control on medical education limits the scope, variety and options available to students. More importantly, Cuba’s hesitation—whether it be based on material or ideological conditions—to develop other professional level, health training programs and commitment to centralized health decision making compromises the depth of knowledge and services required by a population that presents with a variety of chronic and disabling medical conditions.

The state also holds full authority for the medical diplomacy program, inflating medical school admissions beyond domestic needs, to staff international missions. From a Cuban perspective medical diplomacy has certainly been economically and symbolically effective. Yet the medical diplomacy program is not universally accepted. Medical organizations and physicians in Venezuela have sought legal action to bar Cuban doctors from practicing. Resistance to the socialist model, questionable qualifications of Cuban doctors, and taking jobs away from native physicians are cited as reasons for dissatisfaction with Cuba’s doctor export program (Malapanis & Catalán, 2003). Additionally, the export of physicians has placed a strain on the family doctor system due to manpower limitations (Perez, 2008).
Coupled with the medical diplomacy program is Cuba’s development of virtual infrastructures. Cuba’s internet and telecommunication technologies in the form of INFOMED -the national health statistical database- is charged with the mission of promoting communication between the Cuban National Healthcare System and its healthcare workers. The site posts national health statistics, scholarly articles and national reports. I accessed the health statistics reported in this chapter from INFOMED with ease. An additional objective of INFOMED is to disseminate information and market Cuban healthcare services to the international health community with advertisements of workshops, medical school opportunities and consumer health services at competitive prices (Séror, 2003). Although, due to national internet restrictions, most Cuban citizens cannot access health information from INFOMED.

Brotherton (2005) presents two views of the Cuban public health system. One perspective sees through the lens of social control, positioning Cubans as unknowing actors whose everyday lives are shaped and controlled by health policies and surveillance activities. The alternative view recognizes Cuba as a model for health care reform on an international scale. Based on my experiences and observations in Cuba, each perspective has merit and underscores the tensions, complexities and contradictions of the Cuban health care system in particular, and Cuba in general: the push and pull of structure and agency. Keeping these alternative views in mind, Brotherton’s chief concern is that both vantage points reify and assign passive subjectivity to Cuban citizens. Interviews I have conducted with mothers of children with disabilities and health professionals suggest support for passive engagement of the individual in health care interactions. Brotherton
argues that in Cuba new identities are emerging as individuals are becoming active in meeting their own health needs, negotiating contradictions of the state, responding to change and the diminishing role of the state. During my research I have also found support for this position.

Brotherton further contends that in order to gain full understanding of the relationship between the individual and the structure, acts of resistance, agency and autonomy must be grounded historically. According to Brotherton, the historic event that couches new individual interactions with and around institutions of the state is the Special Period. I would agree. Speigel & Yassi (2004) posit that for Cuba to continue to provide health services at its current level and produce highly valued health indicators the state will need to maintain sovereignty in developing and implementing policies to promote health. The tensions of structure and agency amplified during Cuba’s Special Period locate the nation’s health care system at a critical juncture. Will Cuba allow for increased individual agency in health decision-making or will it retain its strong hold on all aspects of the system to ensure symbolic capital and economic gain achieved through the nation’s health care accomplishments? How will Cuba’s health care system evolve?

I submit that the next stage of Cuba’s health care system development will be characterized by the following strategic changes to its model. First, focus will shift to the development of programs and services that meet the needs of individuals with chronic disease and disabling conditions. As indicated by the implementation of the National Priority Program in 2001, disability services and knowledge of the needs of children and adults with disabilities are grossly undetermined. Cuba has made remarkable
accomplishments in addressing and improving general population health status, controlling acute and infectious disease and building an infrastructure to provide primary health care. Attention to secondary health care through expansion of the polyclinic’s services and staffing is in progress. The next natural stage is to develop capacity and infrastructure to provide appropriate and accessible tertiary care in the form of rehabilitation and community-based services.

The Special Period exposed gaps in social support and services required for older adults, individuals with disabilities and families with low resources. In 2002 Fidel Castro called for Cuba’s second revolution:

We are working on a new stage in the construction of socialism… working on new concepts…. We hope to bring about a comprehensive educational culture…. We are working so that every Cuban child has some opportunities and possibilities. I would say that we are in a higher state of development, a qualitative state of [social] development…. We are embarrassed by the things we have not done. (Castro, Public presentation at Cojimar, 2002)

The second component of Cuba’s health care development centers on strengthening the link between social support and health services. Reports from mothers and rehabilitation staff surveyed and interviewed throughout the course of my study underscore the need for institutionalization in both areas. This initiative may be formed at the organization level soliciting support from the CDRs and FMC but needs to trickle down to the family and community. The scope of health care professionals and paraprofessionals will be broadened to support the integration of health and social services. Rehabilitation personnel, special educators and nursing aides are required to
fully address the comprehensive needs of the elderly, families with low resources and adults and children with chronic conditions and disabilities. The expansion of the health care workforce will relocate some health care decision making from the family doctors to other health providers and begin to open space for individual and family participation in health management. Cuba’s development of disability services provides fertile ground to evaluate and implement new forms of health service delivery.

**Disability Services in Cuba**

Cuba’s early post-revolutionary health care system did provide some perfunctory services to individuals with disabilities, but development with a comprehensive and systematic approach to disability services was not actualized until 2002 (see Appendix B). Jorge E. Martin Cordero (2004), President of the Cuban Society of Physical Medicine and Rehabilitation acknowledges the role of organizations, institutions and international agencies in supporting the rights and needs of Cuban citizens with disabilities between 1959 and 1992, in his presentation *Rehabilitation in Cuba—Past, Present and Future*. The state’s first disability initiative was implemented in 1982 with the formation of Action for People with Disability. This program provided universal medical access to individuals with disabilities, created organized rehabilitation programs, developed special education schools and opened 24 homes for the physically and mentally handicapped.

The period between 1982 and 1992 witnessed accelerated screening of the population to “diminish the incidence as well as the social impact of disability” (Cordero, 2004, p. 2). During this time frame a diminished rate of cardiovascular malformations,
spina bifida, Down Syndrome and sickle cell anemia were noted. Feinsilver (1993) reports that Cuba’s enhanced genetic screening during the late 1980s had a twofold outcome; therapeutic abortions for infants identified as not being viable lowered the infant mortality rate and reduced the costs associated with severely disabled infants. In 1987 genetic studies were performed on over 80 percent of pregnant women indicating 505 cases of neural tube defects that led to 495 abortions. Of the 39 women identified through amniocentesis as carrying an infant with Down Syndrome, 32 terminated their pregnancy. Although women are not pressured to abort, Feinsilver posits that many doctors justify termination of a pregnancy in light of the anticipated quality of life for the child and family. Another source infers that therapeutic abortions are strongly advised for women to prevent congenital abnormalities and to maintain the national infant mortality rate (Brotherton, 2005). Cuba’s attitudes toward prenatal testing and genetic screening send an implicit but strong message to women and families with children with disabilities raising issues of stigma and social approval in this cohesive collective environment. Prevention of disability through biotechnology remains Cuba’s primary approach to the issue.

The Cuban Association for the Blind, the Cuban Association for the Deaf and the Cuban Association for Individuals with Limited Physical Motor Function were established in 1992. These nongovernmental organizations interface with the Cuban government around issues relating to accessibility, transportation, education and employment of individuals with disability. Due to economic limitations imposed by the Special Period, the phase between 1992 and 2002 demonstrated minimal growth in
rehabilitation services. Notable accomplishments during this time include the expansion of the Julio Diaz National Rehabilitation Center and the first national rehabilitation scientific sessions and congress.

In 2002 the Cuban government was in the middle of its national investigation of disability and had begun to develop rehabilitation centers in the polyclinics. By 2003 Cuba was able to identify for the first time, the number of individuals with disabilities, disability types, distribution by county and demographics of the disabled population. Cuba’s national survey indicated that 366,844 people within the country of 11 million had some form of disability (Rodriquez Alvarez, 2007). Reported disability incidence rates vary from 2.23 to 3.26 for each 100 inhabitants (Rodriguez Alvarez, 2007; Cordero, 2004). Mental retardation is the leading type of disability in Cuba accounting for 38 percent of the disabled population, physical disability follows with 25 percent representation, visual disability is noted in 13 percent and mental disability accounts for 10 percent of those identified as disabled.

**Key Points**

Cuba’s Special Period in the Time of Peace played a pivotal role in affirming the strengths of the nation’s esteemed medical model and its limitations in meeting the needs of the changing health profile of chronic illness and disability. The nation’s health ideology served the state well, providing political legitimacy, symbolic capital and economic resources through its maintenance of the primary health care system during devastating economic crisis, renowned health care indicators and export of physicians.
and Cuba’s brand of medicine internationally. The Special Period also revealed the contradictions between the outside perspective of Cuba’s health care system and the actual realities of individual experiences, particularly those with chronic illness and disabilities. Cuba’s respected medical model of community-based primary care is anchored in the principles of preventing disease and reducing illness. The physician is the primary provider of all services. Cuba’s health care system is centralized with a top down approach with a focus on primary health indicators. Collective participation is key to the achievement of health indicators. Health brigades are often employed to reinforce preventive health initiatives such as childhood vaccinations, prenatal genetic testing and women’s breast cancer screenings to prevent or eradicate disease. This structure is very effective when addressing acute illness or disease yet limited in meeting the population needs of chronic illness and disability.

Although chronic illness or disability can be prevented through preventative activities or health screenings, it most likely cannot be reversed or eradicated when it is present. Hence while the formation of brigades, primacy of physicians and a pure medical model of eradication and remediation are useful in primary care, new approaches that include other health professional roles and attention to the social support systems to assist those with disabilities and their families are required. Individuals with disabilities and their caregivers at present appear to be located on the fringe of the health-care system, assuming a position of liminality, somewhere in between the medical world and the social context. Cuba’s construction of disability from a strictly medical perspective
overlooks the everyday realities of those with chronic illness subjective experiences, their situated position in the social fabric and interactions within the health care system.

Cuba’s economic crisis also brought attention to the tensions of collective identity and individual practices in accessing health services and resources. Harsh material conditions led individuals to access medications and medical supplies through the informal economy while at the same citizens were enlisted to take on the collective burden of power outages, decreased rationing of monthly food supplements and lack of household supplies and material resources. The state implicitly sanctioned the black market economy as it essentially satisfied the collective’s need for resources formerly provided by the state. Nonetheless the state’s position and response to the collective’s arrangements within the informal economy began to tip the scales in favor of the Cuban citizen’s allegiance in practice to individual needs as the ideological collective identity was challenged. As noted by Brotherton (2005) the state’s offering of alternative mechanisms in which to obtain medical resources moved some Cubans from the role of passive subject to active health consumers. Collective participation in health initiatives, specifically within nongovernmental organizations such as the Federation of Cuban Women and Committees for the Defense of the Revolution, began to experience a reduced role in supporting and contributing to national health programs. The role of these revolutionary based organizations were notably under-represented in the care of individuals with disabilities, reinforcing the contrast between outside perspectives and the inside experiences of families caring for their disabled children.
Cuba’s Ministry of Public Health reported in 2006 that 1.5 million Cubans were treated in the 454 comprehensive rehabilitation units of the nation’s polyclinics and hospitals (Cuban Ministry of Foreign Affairs, 2007). Cuba’s disability services are in the early stages of development. Success is noted in the state’s rapid response to the findings of the National Investigation, with the expansion of treatment facilities and a disability workforce. What remains to be examined and addressed in Cuba’s journey is capturing the essence and practices that represent the everyday experiences of individuals with disabilities, along with close consideration of their families and caregivers and how structural conceptions and changing institutional arrangements impact understandings and the location of individuals with disabilities within the society. In his 2004 report to the International Society of Physical and Rehabilitation Medicine Dr. Cordero identified understanding the needs of Cuba’s patients as a future priority. This study seeks to assist Cuba in meeting this goal through the voices of mothers who care for their children with disabilities in Cardenas, Cuba. An examination of the literature follows to situate this study within the bodies of knowledge relating to structural organizations, cultural conceptions of disability and motherhood; considered with the experiences of women caring for children with disabilities. Multiple theoretical frameworks are explored to evaluate and understand the study findings and complexities of structure, culture and agency in the daily lives of women who mother children with disabilities in this study’s specific socio-cultural context.
CHAPTER 3
MOTHERS OF CHILDREN WITH DISABILITY: PERSPECTIVES, INTERPRETATIVE FRAMEWORKS AND SUBJECTIVE EXPERIENCES

“It is all about the girl, the whole day she is dependent upon me.”
—Belkis, 3/14/09

A woman caring for her daughter with cerebral palsy spoke these words as she presented a description of her daily routines. Other mothers echoed this sentiment as they conveyed their challenges in balancing everyday life. They examined their individual identities as self and mother, made sense of their children’s conditions and needs, and evaluated the opportunities available to themselves and their families. The depth, scope and subjectivity reflected in Belkis’ simple statement may go unnoticed by the healthcare worker providing services to her child. Belkis presents a picture of a fused mother-daughter dyad, a single unit that denies personhood and agency to both (Glenn, 1994). Expressions of real life feelings, notions of a mother’s invisible and unpaid work and the burdens of getting and using professional services onto the home and family are each embedded in Belkis’ response (Smith, 2003). Dorothy E. Smith advocates a method of research inquiry that begins with an individual’s everyday life and aims to uncover the social relations and institutions that make the organization and activities of everyday life invisible. Activities such as sitting quietly for hours at a rehabilitation center waiting to be called in for a physical therapy session because the institution does not schedule timed
appointments, carrying and hitchhiking with your child to all activities due to lack of transportation and setting aside time in your day at home to provide prescribed exercises, each consume time and add additional burdens to the daily experiences of mothers caring for their child with disability and often go unnoticed by family members and systems of social support. Entangled within this web are the ever-present influences of structure and culture on the conceptions, expression and expectations of motherhood, caregiving and disability.

**Structure**

Sewell’s (1992) conceptualization of structure as a profoundly cultural phenomenon is useful in understanding the location and function of culture in Cuba. As noted by Feinsilver (1993, p. 16) “although symbols and myths are pervasive in all societies, they are an integral part of everyday Cuban consciousness.” Sewell’s description of culture is based on an anthropological view that sees culture as “what people know” (p. 7). Society is understood to be ideologically constituted, with ideology informing the structure of institutions and the attitudes of the population (Sewell, 1985). In Cuba ideology maintains a prominent position in the formation of institutions and patterns of social interaction. Particular aspects of Cuban culture make Cuba’s social structure distinctive.

Solidarity, collectivity, and core tenets of socialism (i.e. distributive equality), form Cuba’s ideology and ground the state’s role in caring for its citizens and citizens caring for each other. The principle of distributive equality serves as the bedrock of the
nation’s health and educational institutions. The influence of these ideological principles in relation to individuals with disability is noted in comments from health professionals and individuals with disabilities. When questioned about role of individuals with disabilities within Cuba’s social structure a physician representing a governmental organization in Cuba commented, “We Cubans are very solidarity (sic) with people who have disabilities, from a young age we help them cross the street... big thing in this country is our solidarity for children who are disabled” (PJ, 2003).

The director of a clinic for children with neurological disability acknowledged the roles of solidarity and collectivism in meeting the needs of the children he serves:

I think that solidarity among human beings is extremely important. I think that Cubans have always had a feeling of solidarity in our country but we have gone through very difficult situations lately…. In Cuba we all share the responsibility of children with disability… it is the responsibility of the collective. (RJ, 2003)

An individual with disability also cites solidarity’s role in social interaction.

Maybe different [in Cuba] is the fact that now you go out on the street and no matter how bad things are there’s always someone ready to help you. That’s very common to Cubans and it also very common of you to say of Cubans we always laugh at our necessities so that’s a way of making us stronger and I think that is the main difference… yes, it’s a part of solidarity, it is true, it is undeniable. (LA, 2003)

These remarks reflect not only the close relationship between Cuba’s patriarchal structure and cultural values, they also underscore the society’s approach to caring for its citizens, particularly individuals with disability. The comments also suggest an attitude of charity or moral responsibility towards those with disability. At the same time these
observations obscure organizational and material limitations in meeting the needs of those who are disabled, opening up debate over the primacy of economic conditions or cultural ideology in shaping individual agency and social interactions surrounding individuals with disability.

Sewell’s notions of agency encompass both collective and individual expressions of empowerment. However, the type of agency enacted is contingent upon the social structure in which the individual or collective is situated. Hays (1994) builds upon Sewell’s conceptualization of structure and agency and assigns a more active role to agency in social construction of phenomenon viewing agency as occurring along a continuum of social reproduction and social transformation. Hays states that under particular historical conditions, such as diminished legitimacy of structural forms, shifts in organizational power and changes in the cultural environment, structurally transformative individual agency is made possible. In Cuba, the historical circumstances of the Special Period provided an opportunity to examine disability and created a space for an institutional response to the social challenges manifested during the economic crisis. Static institutions and social arrangements began to be evaluated not only at the structural level but also at the level of subjective experiences.

Keeping in mind social science’s ongoing efforts to reconcile competing perspectives of structure and culture as well as structure and agency, Titchkosky (2003) suggests that disability can provide a prime location for analyzing the role of culture in reifying, governing and locating individuals within a particular social phenomenon. Drawing on Foucauldian notions of governmentality, Titchkosky holds that society
conceives disability as a problem in order to legitimate the state’s role in governing the problem it has defined. Consequently, the state sets the parameters for identification, participation and exclusion of those with disabilities based on its constitution of the phenomenon. In a society such as Cuba that views disability as primarily a biophysical occurrence, it is essentialized as a physical impairment with limited expectations of improvement. Thus, individuals with a biological defect are seen as lacking the full capacity required for participation in the society. Society then approaches this problem procedurally with the intent of controlling or preventing the occurrence of the event and categorizing this special group. Questionnaires, surveys and counting are procedures consistent with this conceptualization of disability. Documentation of individuals and conditions further distinguish the disabled as an excluded group. Additional quantitative information verifies the unified experience of disability and reinforces the state’s conceptualization of this problem.

Cuba’s National Disability Survey is offered as an illustration of Titchkosky’s thesis. The Cuban state defines disability from a medical, bio-physical vantage point. As such the state’s response to this problem took on a procedural, data collection approach in the form of a national survey. The individuals identified in the survey as having a physical or cognitive impairment were categorized as disabled. Enhanced prenatal testing, neurological and genetic screening, increased rehabilitation services and creation of specialty programs are outcomes of the state’s investigation of disability.

Westbrook, Legge and Pennay (1993) evaluate the role of political and social structure on interpretations of disability by examining the attitudes of health professionals.
in international communities toward individuals with disabilities. The researchers find that societal structure, that is whether an individualistic or collective attitude is dominant, is most influential in accounting for cultural differences in individual social behavior toward those with disabilities. In collective societies, disability is more likely to be kept a secret. The expression or presence of disability is socially controlled through the assignment of shame and stigma to those with disability with extension of these attitudes onto the families. Families in collective societies are expected to assume a primary role in the care of the disabled and are typically provided social support to assist this process. Due to the stigma attached to disability, families are more likely to find a more supernatural explanation for disability and are less likely to report it to health officials. In contrast, the researchers find that in individualistic settings disability is socially managed through assignment of guilt. When compared to collectivist groups, courtesy stigma, that is extension of stigma to family members, is less likely to occur. Overall acceptance of disability is linked to societies with high standard of living, less centralized power and more reliance on a scientific model to understand disability.

**Institutionalization of Disability**

Disability is widely acknowledged to be a socially constructed phenomenon (Hughes, 2002; Gordon & Rosenbaum, 2001). While disability is recognized as a product of the social context, the medical profession is the key actor in assigning the label of disability to individuals with physical, emotional or cognitive impairments. Toward that end the medical model serves to inform the dominant discourse that surrounds disability.
(Lalvani, 2008). The medical model is a prevalent view in many societies, yet it is not a sociological theoretical position. It functions as one of a variety of models developed in an effort to provide a framework for identifying, understanding and interpreting disability. Advancement of medicine during modernity is considered to be an important contributor to the framing of disability as the expression of physical impairment and negation of health and order (Hughes). As a consequence, the collaboration of modernity and medicine resulted in the conception of disability as a medical condition. The medical model of disability can be traced to coincide with Foucault’s work focusing on modern biomedicine at the end of the eighteenth century. Hughes (2005) maintains that the advent of a biomedical approach set in place distinctions between normal and pathological bodies.

The biomedical perspective sees the individual with disability as having a defined long term or permanent physical impairment that is either congenital or acquired. Services are designed to lessen or correct the condition, promote recovery and adaptation. This model takes on the perspective that disability is defined as an impairment to be corrected through rehabilitation, or eliminated through exclusionary practices or extreme measures evidenced in the eugenics movement (Hughes, 2002). Critics of this model cite the model’s emphasis on impairment, the authoritative role of health professionals in distributing knowledge and decision making, and neglect of contextual influences on
disability as limitations of this perspective (DePoy & Gilson, 2004, Verebrugge & Jette, xxvi 1994).

The medical model of disability is the dominant lens through which Cuba defines and explains disability; however, subtle actions at the community level have resulted in the incorporation of social aspects of disability into rehabilitation practices (personal communication & notes, RJ, 2004). Since the time of Cuba’s revolution and restructuring of the health care system in the early 1960s, the state has implemented a strictly impairment based, medical approach to the management of disability. The provision of rehabilitation services is grounded in concepts associated with defectology. Defectology is described as “an integrated scientific discipline that embraces the study and education of all handicapped children and adults” (Lubovsky, 1974, p. 298). This approach has its roots in the Soviet Union during the early 1970s and was adopted in a majority of socialist countries. Defectology views disability along the lines of the medical model, defining individuals with handicaps as those with physical or mental defects that hinder their development within typical environments. The defectology perspective supports segregated teaching environments as optimal settings for individuals with disability. As such, a system of diagnostic-specific specialty schools staffed by defectologists is available for those with disability.

Concepts of defectology and the medical model retain a primary position in the formation of rehabilitation services and educational programs in Cuba. Yet alternative

xxvi Although Verebrugge critiques the medical model, their disablement model is limited to physical and functional aspects of disability without consideration of the social environment, attitudes and access.
and competing perspectives of disability are now present in international academic discourse and in practice in advanced societies and are emerging in low resource nations. Nevertheless, as Landsman (1998) notes, vestiges of the medical model concepts continue to be observed in biomedical prenatal technologies aimed at preventing or eliminating potential physical and cognitive impairment. Prenatal testing, genetic and neurological screenings are practices firmly grounded in the medical model’s focus on reducing and eliminating the occurrence of disability. Cuba, in concert with other scientifically developed nations, has taken a biotechnical approach to prevention and reduction of disability, supporting extensive prenatal testing for all women and boosting genetic screening programs.

The social model of disability was developed in response to the limited scope and explanatory power of the impairment based medical model. This model has held a prominent position in the United Kingdom\textsuperscript{xxvii} and is posited to be a product of postmodernism’s attention to forms and expression of difference (Hughes, 2002). The social model explains disability from a contextual perspective and makes the claim that negative societal attitudes, barriers in the physical environment, limited physical and communication access and exclusion of rights and privileges are obstacles to individuals with disabilities’ full participation in society. The social model is grounded in appreciation of the individual with disability and values the collective experiences of the disabled (DePoy & Gilson, 2004; Humphrey, 1999). Hughes (2002) argues that the

\textsuperscript{xxvii} Most of the sociological literature surrounding disability has come out of the UK. US sociology has been markedly absent in this discourse (Hughes).
social model of disability has been instrumental in the formation of a disability culture
and in turn has effectively contributed to the disability social movement, a mechanism for
collective agency.

DePoy and Gilson (2004) build upon Hughes’ view stating that the charity model
is inherently hegemonic and symbolizes the marginalized economic and social location of
the disabled. The authors raise the question of who benefits from viewing disability as a
moral obligation. DePoy and Gilson state that hegemony theory is important to the study
of disability to allow analysis of disability definitions and practices from the perspective
of competing interests, power relationships and diverse values. The authors take the
position that opposing medical and social models of disability are insufficient in
understandings of this phenomenon and call for a framework that presents the essentiality
of the socio-political context in establishing how categorical definitions and responses to
people with disabilities are shaped and changed over time.

Cuba provides a rich context in which to study the complexities of disability as its
highly institutionalized socialist structure naturally leads to questions concerning how the
state defines and manages social phenomena and how individuals, particularly those in
marginalized groups, negotiate relationships within the structure. Cuba’s historical period
of economic crisis and social development, with its marked attention to disability, invites
notice to the state’s role in opening of spaces for individual participation in re-
configuring disability and shaping effective and relevant disability services. In other
words, disability in Cuba is changing. With this change issues of structure, agency and
the subjective experience of disability come to the forefront inviting the voices of those
with disabilities and their caregivers in configuring new social arrangements, identities and conceptions of disability. How then may the literature inform our understanding of women’s subjective experiences in providing care to their children with disabilities?

**Mothering a Child with Disability**

The literature relating to the experiences of mothers with children with disability identifies challenges faced by caregivers and the strategies they employ to reconcile contradictions inherent in their roles as mothers and society’s construction of disability. Research topics of gendered caregiving, assignment of responsibility for a child’s condition, and tensions in parent–professional relationships dominate writings intended to reveal the subjective experiences of women who through their child are firmly located within the world of disability. Similar to literature that examines disability from a structural level, the academic discourse that surrounds the experiences of mothers with disabled children speaks to notions of disability configured through dividing practices used to categorize and manage individuals and behaviors. Where contemporary analyses of disability construction and governance focus on influences of context and power relations, the study of stigma and caregiver burden occupies a primary space in interpretations of disability at the subjective level of mothers with challenged children. However, an alternative discourse that offers narratives of resilience related to the joys of mothering a child with disability and maternal caregivers as socially situated agents is now emerging (Kearney & Griffin, 2001; Lalvani, 2009, Levine, 2009). The literature in essence collectively seeks to provide answers to the fundamental question of how
mothers of children with disabilities construct the meaning of their child’s condition, reconcile their perspective of motherhood in relation to their child, and act as agents of change within their particular social, cultural environment.

Landsman (1998) begins the discussion by locating her analysis of mothering a child with disability within the context of biotechnology. Landsman, as well as other researchers, brings forward the “paradox” encountered by mothers as they negotiate the identification and understanding of their children’s diagnoses, accept or deny aspects of their children’s condition and experience the joys and sorrows of mothering a disabled child. Landsman finds that while women are offered reproductive choices, at the same time they are assigned blame if an “unfavorable” outcome occurs. As a consequence of their decision, mothers of young children with disability report being challenged by cultural understandings of normalcy as they struggle in connecting with the personhood of their children. To affirm their identities as mothers, women tend to place their child with disability within their maternal narrative, conferring roles such as victim, survivor or fighter to the child.

Larson’s (1998) study of Mexican women with children with severe disability suggests a cross-cultural resonance of the themes uncovered by Landsman. Larson finds that Mexican mothers of disabled children also raise the issue of personhood of their children. The women in this study link their subjective well-being to their success in mothering as they grapple with their sense of control. Larson uncovers mothers’ tensions between their current circumstances and desires for the future as they accept their child on an emotional level but deny their child’s abilities from a cognitive perspective.
Mothers are found to love their child and yet want to erase the child’s disability. Contrary to medical opinion mothers continue to hope and seek solutions to ongoing problems with unrealistic expectations leading to disengagement and despair. Smith, Oliver, Boyce and Innocenti (2000) also acknowledge the influence of mothers’ sense of control in relation to their child with disability. The researchers contend that mothers’ belief that they have control over life events is an important indicator of their capacity to be involved in their disabled children’s treatment program and in taking initiative to procure support and services.

Mothers of children with disabilities adopt a variety of approaches in an effort to reconcile their maternal roles and promote the personhood of their child. Women take on advocacy roles, seek emotional and social support, and acquire information to enhance their understanding of their child’s condition and buttress their mothering through subtle and overt expressions of agency (Landsman, 1998; Shapiro & Tittle, 1990). Landsman notes that “real motherhood” is an issue for mothers caring for disabled children. The women in her study reject the idea of a tragic life that is associated with having a disabled child and instead adopt an identity of commitment, nurturing and advocacy born out of recognition of the humanity of their child.

Gendered Caring for Children with Disability

Families of children with disabilities tend to follow traditional arrangements in the home with gendered roles and caregiver responsibilities. The fathers’ domains center in the outside world and women assume tasks within the family (Traustadottir, 1991).
Gender is one of the dominant ways in which individuals organize their lives (Lorber, 1994). Society includes gender in its division of labor and generally assigns women the responsibility for children and those who cannot take care of themselves. Gendered forms of caring for those with disability are prevalent in the literature and cut across social and cultural contexts. Cuban society has undergone radical social transformation since the time of the revolution, though gender studies did not emerge in Cuba until the mid 1980s (Sarmiento, 2003). The opening of the gender discourse, albeit a mostly historical and cultural analysis of Cuban women’s roles, was a precursor to the nation’s 1992 constitutional reforms established in the Family Code of 1975 that strengthened gender equality principles in the workplace and education (Sarmiento). According to the United Nations Report of 2000, despite women’s high level of education, traditional sexist patterns continue to exist as in many families in which women continue to be primarily responsible for most of the domestic chores, child care and caring for the sick and elderly.

Although Sharon Hays’ (1996) examination of the cultural contradictions of motherhood is based on findings within a capitalistic society, her insights are helpful in understanding the construction of the good mother in Cuba. Hays holds that patriarchal societies, such as Cuba, support women as the caregiver due to gendered characteristics of nurturing and intuition. Expectations of maternal denial of self interest and personal goals may reflect socialist or collective notions, while at the same time they contradict legislative gender equality. Sarmiento (2003) points out that, although legal equality for men and women exists in Cuba today, a gendered approach is useful in revealing small
and omitted things in everyday life and understanding their meaning in society. A
gendered perspective that is linked to power relations, socio-political concepts and
ideological notions helps to understand structures of inequality.

Women who care for their children with disabilities are devalued in three ways:
“first they are caregivers, then female and finally they are associated with their child’s
disability” (Wickham-Searle, 1992, p. 6). Sarah Green, a sociologist and parent of a child
with disability, has examined the impact of structural aspects of stigma on the gendered
caregiving practices and attitudes of mothers with children with disability in the United
States. Green has explored this topic from perspectives of the lived experience of
discrimination toward disability, the influence of stigma on maternal attitudes toward
residential placement and the association between perceived caregiver burden and socio-
structural constrains. Green’s studies reinforce the complex processes and negative,
though varying, consequences of stigma on maternal attitudes, decision-making and
perceptions of caregiving. She finds that the stigma of children with disability takes on
many forms and is spread to other family members. Mothers of children with disabilities
report feelings of separation from others, reduced self-worth, depression and social
isolation—examples of indirect stigma. Acts of hostility and otherness associated with
the separation component of stigma are viewed by the mothers as most problematic and
more difficult to overcome than overt acts of discrimination (Green, Davis, Karshmer,
Marsh, & Straight, 2005).

McGuire, Crowe, Law and Van Leit (2004) reinforce Green’s findings of
maternal isolation, confusion around self-identity and the impact of the environment on
personal well-being. The researchers bring into the discussion the relationship between gender and burden of care finding that women whether single or living with a spouse or partner were given the primary person responsibility for the care of their disabled child. Mothers reported being uncomfortable leaving their child, experienced guilt in not doing everything possible for their child, and expressed doubt around being able to meet his or her needs. Mothers often related a lack of social support due to a lack of understanding about what was important to the mother and child.

Health professionals’ interactions with families of children with disabilities significantly influence maternal identity, attitudes and practices when caring for their disabled child. Shapiro and Tittle’s (1990) examination of Hispanic mothers of children with disability showed that interactions with professionals had the greatest impact on mothers’ attitudes toward their child’s limitations. Health professionals are in a unique location within the healthcare system as they straddle the structural and subjective levels of disability. Health professionals often represent the ideology of the structural framework in which they are located. They adopt conceptions of disability as a biological or social construct; convey or resist cultural and institutional attitudes toward disability and support or challenge the subjective experience of disability and the individuals they serve. Health professionals also assign meaning to disability and may attribute responsibility or form judgments about women’s roles in the birth or care of their child with disability.

In her work on parent–professional relationships, Konrad (2005) finds limited accounts of mothers of children with disabilities and their relationships with
professionals. She notes that mothers tend to be dichotomized by rehab providers as victims or heroes. Mothers are generally dissatisfied with parent–professional relationships due to miscommunication, blame placed on mothers and underestimation of parent’s emotional needs. Mothers want professionals to understand their emotional experiences, but at the same time they are afraid they will be perceived as unable to cope with their child’s disability. Larson (1998) suggests that health professionals often view families of disabled children as part of the problem, viewing parents as having unrealistic expectations and failing to truly understand or cope with the problem of disability. Families report encountering misunderstandings, obstacles when pursuing information and feelings that health professionals are assessing them.

The voices of the caregivers of individuals with disability, specifically, their mothers are notably underrepresented in the disability discourse and thus are not apparent in Cuba’s process of redefining disability. Culture and context play an essential role not only in the daily life experiences of mothers caring for a disabled child but also in structural conceptions of motherhood and disability, institutional arrangements and the delivery of services created to meet the needs of individuals with disabilities and their families. Llewellyn, Thompson and Whybrow (2004) contend that across social and cultural contexts, it is the mothers of children with disability that typically endure the impact of discrimination or disadvantage. The researchers note that although all mothers are required to engage within institutional structures, mothers who parent children with disabilities are often required to go beyond typical institutional patterns and systems to access the services and resources needed in the care of their children. Even though
women in this study reported positive aspects of their actions, the researchers conclude that the mothers’ extension of their caring to the broader social context may not be freely chosen and serves to “reinforce existing gendered expectations and care practices with disabled children” (p. 303). Furthermore, the researchers stress the need for contextual and nuanced understandings of motherhood when examining the lived experiences of mothers caring for their children with disabilities.

Conceptions of Motherhood: Context and Practice

Motherhood and notions of mothering are multifaceted, as the construction of mothering takes on forms not only in the realm of ideas but also in social interactions, socio-cultural institutions as well as collective and individual identities (Glenn, 1994). Mothering, perhaps more than any other social construct, has been subject to an essentialist interpretation, that is, mothering is seen as natural, universal and unchanging. Yet as Glenn notes history and social variation confirm that mothering is socially constructed, not simply biologically determined. Conceptions and expressions of motherhood are not formed nor do they exist in isolation of other social and political structures. Historical and material conditions in addition to the specific cultural context impact maternal roles and identities (Hill Collins, 1994). Conceptions of mothering are formed through the actions of men and women over time and in particular circumstances, thereby underscoring the role of agency in understanding mothering as a social construct.

Patricia Hill Collins (1994) observes that an understanding of mothering from a feminist perspective overlooks the contextual aspects of women’s experiences with
motherhood. Hill Collins argues that the assumption that all women are situated in contexts in which they can see them themselves as individuals in search of personal autonomy is false. Women also identify themselves as members of communities that are challenged by material conditions and struggling for survival. Thus, it is essential to acknowledge that race, class, the socio-political context and power structures influence women’s experiences of mothering and the construction of their identities. Therefore, the examination of mothering practices without reference to the social context provides only a partial, ungeneralizable perspective of mothering. Hill Collins suggests that research instead ought to examine the ways women assert their own agency within their particular social context as they define their own roles and attain the support and resources needed to care for their children.

Sarmiento (2005) asked participants to respond to popular sayings relating to Cuban women. One of the sayings offered to participants were “Women have to be mothers in the first place, then workers and lovers” (p. 13). Of the fifteen men who responded to this statement, thirteen reported that this statement was true. The women in the study expressed a somewhat different sentiment indicating that the three roles identified in the statement must be taken on simultaneously, thus not privileging the role of mother over worker or lover. Some of the responses offered by the men included: “to be a mother is the basic responsibility of a woman, the most important role of a woman is to take care of her children, and Cubans always say: my mother goes first of all” (Sarmiento, 2005). Several women that I interviewed during my research stated “to be a mother is the most joy any woman could have.” As noted by Lutjens (1995) the cultural
transformations experienced publicly during the Cuban revolution lagged behind in the
domestic sphere as neither motherhood or notions of femininity have been rejected by
Cuban women.

Grounded in Marxist theoretical perspectives and Cuban culture, the Cuban family is viewed as the basic unit of society (Friones, 1993). The Cuban revolution provided women with a socialist framework that supported and offered opportunities for participation in production, education and revolutionary activities such as agricultural and health brigades. The Federation of Cuban Women was created to organize the participation of women in revolutionary goals. Lutjens (1995) however, argues that women’s organizations in state socialist countries tend to have diminished autonomy as the issues addressed within the organization are not centered on concerns identified by women or reflective of feminist efforts, but instead are subordinate to the priorities of the state. The Cuban Family Code instituted in 1975 extended equality for women to the domestic sphere specifying the role of men in sharing responsibility for household work and childcare. Still, Cuban women continue to take on the bulk of childrearing, assume responsibility for the “second shift” and function under a patriarchal structure that has been difficult to eradicate in spite of state legislative efforts (Toro-Morn, Roschelle, & Facio, 2002). Safa (2009) contributes to this discourse as she calls into question contemporary structural forces that have led to an increase in female-headed households associated with the prevalence of the consensual unions, extended family situations and increasing economic inequality as products of the nation’s economic crisis.
The literature shows the dramatic effect Cuba’s Special Period had on the everyday experiences of women and the return of traditional gender roles. As the nation faced the challenges of economic devastation the women endured much of the burden. Unemployment rates were twice those for men. Many women experienced downward mobility as they moved from full-time to part-time employment and shifted from professional positions to less skilled jobs in tourism thus reducing most of the revolutionary gains woman made in the labor force (Safa, 2009). Women additionally took on the time consuming role of *la busqueda*, the moniker for the Special Period survival strategy and everyday search for US dollars, food and necessities within the informal economy (Toro-Morn et al., 2002). The activities that women undertook during Cuba’s economic crisis provide an example of how historical circumstances may influence maternal roles and gendered adaptations.

Advances in modern medicine and biotechnology reinforce a medical model perspective of disability with a focus on prevention, medical authority and economic determinism. However, research also shows that, in collective societies with a highly centralized, top-down approach to decision-making, fostering change in attitudes and practices toward disability is most effective when initiated at a community level.

Structural and cultural specificity is essential to full understanding of the human experience. Culture is presented in the literature as a structural construct and as emergent in individual interactions with “cultural actors” negotiating cultural events as they express their individual agency. The literature relates mothers’ concerns of working the

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Spanish for the search
second shift, caregiver burden, and societal expectations of motherhood as the ideal mother and brings in the impact of material and socio-political conditions that influence mothering in general. Woman mothering children with disability express additional concerns of attachment of blame and stigma to their role as mother, marginalized maternal status and unsatisfying relationships with health care providers. Research shows that mothers with children with disability adopt a variety of strategies to reconcile their identities, procure social capital and acquire resources for their children.

**Conceptual Guide of the Literature**

These key themes put forth in the literature point to the value of women’s voices in elucidating the role of structure and agency in the comprehension of the subjective experience of mothering a child with disability. The question at hand is how do the findings presented in the literature inform or apply to the specific and particular socio-cultural context of this study, Cardenas, Cuba. What are the relationships between Cuba’s structural, institutional and individual levels in defining and locating disability, prescribing patterns of interactions between those with disabilities, their caregivers and professionals, and outside perspectives and inside realities of the lived experiences of women who mother children with disabilities. In the previous chapter, the organizational structure of Cuba was examined in relation to its respected health care system and structural accommodations that the state made in the response to the economic crisis during the Special Period.
Cuba’s organizational structure is highly centralized and as a socialist nation it is based on a foundation of distributive equality. Structure and culture maintain a symbiotic relationship with cultural values of collectivism, solidarity and motherhood supporting socialist ideology and patriarchy. The previous chapter also presented the close association of Cuba’s economic resources and the health care system as noted in the export of physicians and the nation’s brand of health care. In contrast to decentralized organizations with greater social distance between institutions and the larger structure, health and economic sectors in Cuba are situated at the structural level. Hence the state defines and locates disability within the medical realm and confers cultural authority on physicians in the care of individuals with disabilities. At the institutional level, patterns of interactions and caregiver roles, such as the good mother and solidarity, are either socially approved or viewed as contrary to expectations. The structural and institutional level come together to shape the identity and attitudes of mothers who care for children with disabilities as well as the ways they interact with social systems. Due to the dependent relationship between the symbolism of the health care system and economic resource distribution, the structural level has the greatest influence on the individual level.

The practices of mothers of children with disabilities in Cardenas, Cuba are largely influenced by constraints at the structural level. Lack of economic resources, dominance of the medical model of disability and cultural values of women as dedicated mothers locate women who mother children with disabling conditions in invisible contexts of home and the clinic. Though it is not clear if cultural ideology or material conditions occupy the prime location in Cuba’s structural organization. Mothers’
attitudes toward disability are informed by interactions at the institutional level where expected behaviors are codified, judgments surrounding parenting styles are made and disability is often viewed solely as a medical diagnosis. This study seeks to understand if the experiences and perspectives of mothers in Cuba are reflective of what the literature tells us about women who care for their children with disabilities in different sociocultural contexts. This study also seeks to understand the organization and experiences of disability within this specific cultural context and to uncover contradictions or tensions between the outside perspective and the inside reality as women navigate institutional systems in the care for their children. The methods chosen to address this study’s research questions and to additionally enhance my understanding of the role of structural mechanisms in everyday life of mothers of children with disabilities in Cardenas follow in the next chapter.
CHAPTER 4
METODOLOGY

El Centro de Rehabilitacion y Neurodesarrollo in Cardenas, Cuba is the site in which this study takes place. Locally Cardenas is known as the birthplace of the Cuban flag and the home of Elian Gonzalez. Cardenas is also the sister city of Philadelphia, hence my membership in the Sister City Association provided the opportunity to establish an academic exchange program in Cardenas with El Centro. When I first visited Cardenas in February 2002, it felt as though I had traveled back in time. Streets were populated with bicycles and horse drawn carriages. Children dressed in red uniforms held hands with their mothers as they made their way to school. Older adults peeked out of one-story houses with faded paint and shuttered doorways as they viewed the daily bustle of early morning. The town looked tired though vibrant with a strong sense of community and pride. El Centro de Rehabilitacion y Neurodesarrollo was not yet constructed as German workers pushed to have the building completed within the next three months.

Upon my return to Cardenas the following year the Rosa Luxembourg El Centro de Rehabilitacion y Neurodesarrollo, housed in a beautiful rose-colored colonial building on the town’s main street, was up and running providing services to children with

xxix The US–Cuba Sister City Association is not recognized by the US government as an official sister city program.
disabilities and their families. Dr. Jorge Rodriguez, a pediatric neurologist and the founding director of El Centro, provided a tour of the facility and shared snippets of how this children’s rehabilitation clinic came to be. His story not only exemplifies the actualization of personal and professional goals, it also illustrates the role of individual grassroots efforts in supporting and contributing to Cuba’s institutional development surrounding the needs of individuals with disabilities. Dr. Rodriguez’s narrative illuminates the particular cultural approach and attitudes toward disability that are held at El Centro and in turn has informed the design of this study.

The Research Setting: El Centro de Rehabilitacion y Neurodesarrollo

Jorge Rodriguez graduated as a pediatrician in 1977 and then went on to Havana to do specialty training in pediatric neurology. Ten years later in 1987, Dr. Rodriguez’s “life was tested.” After having two healthy daughters, his son sustained perinatal asphyxia during birth resulting in motoric and cognitive impairment. Dr. Rodriguez and his wife, a dentist, traveled to Havana to specialized health centers and quickly understood that the services needed for their son were not available and that the family would “have to deal with it.” The Rodriguezs taught themselves rehabilitation concepts and procedures and sought help from many individuals, including psychologists, physical educators and speech therapists.

In 1992, Dr. Rodriguez was able to put together a small team to work with children with disabilities. The team found space in a historic building assigned to the

xxx Perinatal asphyxia—lack of oxygen during the birth process
Ministry of Education and set up an improvised therapy gym and evaluation room. While working full-time at the provincial hospital in Matanzas, once a week Dr. Rodriguez and his team would work late into the night offering rehabilitation evaluations and exercise to children with disabling conditions. Dr. Rodriguez eventually resigned his position at the hospital and began to train other professionals in rehabilitation at the local polyclinic. Staff training and dissemination of training activities became Dr. Rodriguez’s core value and priority. Dr. Rodriguez initiated training of all pediatricians and neonatologists in the province of Matanzas in early identification of children at risk for disability, emphasizing the importance of early detection and prevention in rehabilitation services.

As Dr. Rodriguez continued to develop his practice and training activities, he collected data and organized scientific sessions that showcased the work of his rehabilitation team. The team was given the opportunity to present their results to the president of the municipality. Videos demonstrating the progress of two children receiving rehabilitation services were effective in soliciting the local government’s investment in supporting the rehabilitation program. However, Dr. Rodriguez still needed a rehabilitation center. “And then,” as stated by Dr. Rodriguez “…the Germans showed up.” The German Communist Party agreed to provide material and physical support toward the construction of Cuba’s first children’s rehabilitation center. In 2000 the mayor of Cardenas gave Dr. Rodriguez the building that had been occupied by Cardenas’s first public school. El Centro opened in the summer of 2002 with few resources and a small team trained by Dr. Rodriguez.
El Centro de Rehabilitation y Neurodesarrollo provides rehabilitation services to children in Cardenas and throughout the Matanzas province. El Centro is proud of its early intervention program initiating evaluation of newborn infants with pre- and perinatal risks as early as 1997. Dr. Rodriguez attributes the diminished rate of children with severe disability at El Centro over recent years to the success of the early intervention program and early identification of children at risk. Consequently, the early intervention program accounts for more than a third of the patient population. Infants at risk for developmental delay or disability are referred to El Centro by the family physician, the local polyclinic or upon discharge from the hospital. The physical therapists massage, stretch and exercise the infants in a variety of developmental positions as mothers, and on occasion fathers, observe the treatment session. Mothers are shown the exercises and instructed to perform the activities at home daily. El Centro views the participation of the mothers as instrumental to the success of their children’s rehabilitation program.

Physical therapy, occupational therapy, psychology for children with learning and behavioral problems, feeding therapy, vision therapy, art therapy, music therapy, dance therapy, color therapy, medical and dental care, parent counseling, genetics and consultation services are available to all children and families. El Centro’s services are comprehensive and accessible. Families are comfortable within the clinic environment often commenting that El Centro is “like home.” Families affectionately refer to Dr. Rodriguez as Jorgito. Jorgito lives less than two blocks from El Centro. He is frequently stopped on the street for opinions or expressions of gratitude and available to meet with a
child or family at any time. Jorge Jr., Dr. Rodriguez’s son born in 1987, works at El Centro doing errands and performing clerical duties. El Centro is a family-centered community that is dedicated to the remediation of childhood disability as well as the promotion of social integration of children with disabilities and their families. Toward that end El Centro has educational, vocational and social skills training classes for young adults with cognitive disabilities, a plastics\textsuperscript{xxxi} group conducted by a local artist for children with attention problems, and a monthly community event that brings children with and without disabilities together in cultural activities.

When asked about his vision for El Centro de Rehabilitacion y Neurodesarrollo Dr. Rodriguez identifies two key objectives—the social integration of children with disabilities in school and other environments and the distinction of El Centro as a rehabilitation center of excellence with a focus on the neuroscience of disability. Dr. Rodriguez sees “real integration” as the disabled child having the same rights as any child and not viewed as “a pity.” He envisions assigning children with disabilities with social diagnoses in addition to identification of the child’s medical condition. He advocates an innovative model of educational integration that requires children with special needs to be located within normal educational programs that make available different learning approaches based on a child’s specific academic needs. As shown in the following passages Dr. Rodriguez is consistently adjusting his vision and program in response to new knowledge as well as effecting change in institutional practices and attitudes toward disability.

\textsuperscript{xxxi} Plastics—ceramics, sculpture
We are a poor country without resources... our vision has increased, has changed.... These workshops we’ve gone through will lead us to brainstorm. I think the center will have to make a big change in its organization. (Jorge Rodriguez, June 2004)

I have seen changes in the therapists from when we started three years ago. The therapists are more integrated, they work together, the quality of their work is different, we have an integrated vision... we now work with the community to get children with disability involved at a more social level... we have added art and music to our rehab program.... At the national level there is a change in the mentality, rehab is a part of the vision... there is more acceptance of disability in the schools. (Jorge Rodriguez, March 2006)

El Centro is a community-based, comprehensive, progressive facility that contributes to the standards for children’s rehabilitation in Cuba. The clinic is loyal to the principles of the nation’s family doctor program, interfaces with the health care system infrastructure and fully embraces the core tenet of Cuban health care—ser humano—see the humanity in each patient and family member. Each member of Dr. Rodriguez’s team participates in research activities and many are pursuing graduate degrees. El Centro is currently exploring ways to provide rehabilitation courses that contribute to staff development and provide economic resources to further develop programmatic services and activities. This novel children’s rehabilitation setting and Dr. Rodriguez’s work are offered as exemplars of the philosophy and guiding principles of Cuba’s health care system.

Dr. Rodriguez’s achievements may best be understood by applying findings from Malcolm Gladwell’s research on “outliers.” Gladwell (2008) finds that extraordinary

xxxii To be human
success is due to a combination of tremendous dedication, opportunity, work that is meaningful to the individual and historical circumstances. The birth of Jorge Jr. augmented Dr. Rodriguez’s dedication and meaning in his work as a physician, motivating him to gain more knowledge and extend his skill set. The Special Period presented historical circumstances wherein disability services and attention to individuals with disabilities garnered national attention. Partnership with an American university and Sister City Association, the donation of clinical space and the support of the German Communist Party afforded opportunities to gain knowledge, clinical skill and material resources. Dr. Rodriguez’s forward thinking also appreciated the position of research and caregivers in securing the foundation of rehabilitation program.

The Development of the Research Proposal

In order to conduct research at El Centro I needed to establish relationships beyond the study site. During my early visits to Cardenas I met with the president of Cardenas, state officials of the Matanzas province, representatives from ICAP, representatives of the Ministry of Health in Matanzas and Havana, the First Secretary for Health and Ambassador at Washington D.C.’s Cuban Interest Section. Over the years representatives from the Matanzas Ministry of Health observed my work at El Centro. Each time I visited El Centro my activities were shared with the Matanzas provincial office. Dr. Rodriguez championed the academic exchange program as we collaborated on program activities and outcomes. A formal proposal for an academic exchange program was submitted to and accepted by the Matanzas Ministry of Health in 2003. A small pilot
study was conducted in 2006 to evaluate the potential of a cross-cultural investigation focusing on the experiences of mothers of children with disabilities at El Centro. The mothers interviewed were agreeable to participation, candid in their responses and welcomed the opportunity to share their narratives. I then began the process of conceptualizing and developing a research proposal that would contribute to understanding of how mothers make sense of their child’s disability and the actions they take in the care of their disabled child in the particular context of Cardenas and in turn provide El Centro with relevant information to support development of programs and services.

In January 2007 I met with Dr. Rodriguez to discuss El Centro’s research agenda and collaboratively develop a proposal that would contribute to understandings of how the mothers whose children receive rehabilitation services experience and explain the phenomenon of disability and the influences of the socio-cultural context on their daily activities. My primary interest in this study was to provide an ethnographic account of women mothering disabled children within the specific structural context of socialism. As the development of this proposal evolved, my attention was drawn to the inherent value of the caregivers’ narratives in informing rehabilitation practice and institutional service delivery, thus underscoring the potential role of the mothers as agents in transforming structural systems and individual attitudes. Dr. Rodriguez’s key objective in regard to his research agenda was to distinguish maternal attributes that support the success of their
child in the rehabilitation program. He hypothesized that a cultural level\textsuperscript{xxxiii} may have a part in how a mother understands and approaches her child’s disability. In addition Dr. Rodriguez felt that it was important that the investigation evaluate mothers’ perceptions of the quality of services provided at El Centro, interactions with the rehabilitation staff and provide the women with an opportunity to identify material resource needs. We agreed to design a proposal that included survey of mothers’ attitudes toward the services at El Centro, interviews to get a sense of how mothers understood their children’s conditions and observation of mother–therapist interactions in the physical therapy gym.

An initial request to conduct a research study at El Centro de Rehabilitacion y Neurodesarrollo was submitted to Cuba’s Ministry of Public Health in March 2007. The request was processed through a variety of offices including provincial and national public health ministries, the donations ministry and the ministry of foreign affairs. With the tireless support of a physician at the National Ministry of Health, a colleague who conducts business in Cuba, Dr. Rodriquez and the staff at the Matanzas Ministry of Public Health, I received a letter of support and authorization to implement this study on July 7, 2008, almost a year and a half after the request was submitted. Upon receipt of the letter of support, the research proposal was submitted and approved by the Institutional Review Boards at Temple University\textsuperscript{xxxiv} and Columbia University\textsuperscript{xxxv}.

\textsuperscript{xxxiii} Cultural level—this notion is discussed in Chapter 7, essentially within the context of this study cultural level is the general term used to describe an individual’s social class.

\textsuperscript{xxxiv} Temple University IRB protocol 11972 approved on September 19, 2008

\textsuperscript{xxxv} Columbia University IRB protocol AAAD3979 approved on October 4, 2009
On January 5, 2009, I met with the Matanzas provincial president and international programs director to review the research agenda and activities and to obtain a Cuban work visa. The study was implemented at El Centro on January 6, 2009. This first data collection point was nine days in length. At the end of this phase, I debriefed with Dr. Rodriguez and the Matanzas Ministry of Health. The Matanzas Ministry of Health and representatives from ICAP also performed a site visit during the first data collection cycle. The second data collection point was seven weeks after my first visit, commencing March 9 and finishing March 15, 2009.

**Research Design**

The primary objective of this investigation is to understand how mothers whose children receive services at the pediatric rehabilitation center in Cardenas view their child’s disability and how their interpretations influence the roles and actions that they take in the care and management of their child. The selection of this research topic was informed by observations and data collected during the development, implementation and evaluation phases of an academic exchange program in Cardenas, Cuba. The data indicated the value of input from families and mothers caring for their children with disabilities in identifying opportunities to develop and advance institutional practice by incorporating the insights and potential collaboration of mothers of children with disability (Tupe, 2006).

This study tests the hypothesis that structural and cultural conceptions of and attitudes toward individuals with disabilities are reflected in the individual interpretations
of mothers of disabled children as it concerns their child’s disability. In turn, individual interpretations influence the actions the mothers take in meeting their child’s needs. The voices of caregivers, particularly mothers, can enhance understanding of the connections between structural and subjective levels of experience and analysis. Understanding the personal experience of mothers can also support the practical goal of contributing to improvements in care. This research project sought to address the following questions:

- How do mothers of children with disability in Cardenas, Cuba make sense of their child's disability in the current socio-cultural environment? How do mothers’ interpretations of their child's disability reflect the structural conceptions and attitudes toward disability and inform the actions that they take in negotiating and promoting inclusion of their child in social and educational environments?

- How do mothers' interactions with institutional structures and personnel influence their utilization of services and engagement in the rehabilitation process? How can the voices of mothers of children with disabilities in Cardenas, Cuba collaborate with El Centro de Rehabilitacion y Neurodesarrollo to more effectively develop rehabilitation services, support the role of mothers in caregiving and promote the social inclusion of children with disability?

- How do mothers of children with disability in Cardenas, Cuba view their role in affecting change in relation to location and participation of children with disability in social and educational environments? What actions can parents or caregivers of children with disability take to promote their children’s inclusion in everyday life and social participation?
Research procedures included a triangulation of methods. Questionnaire survey, audio-taped interactive interviews and participant observation of the rehabilitation environment and processes were conducted at El Centro de Rehabilitacion y Neurodesarrollo in Cardenas. Data were collected at El Centro over two distinct periods, two weeks in January and one week in March, 2009. The cultural environment of El Centro also permitted informal organic interviews with the staff and mothers. These discussions, typically occurring during daily lunch and early morning, were commonplace and provided opportunities to verify information and gain broader understanding of the structural aspects of Cuba’s health care system and rehabilitation procedures at the facility. The study questionnaire was offered to all mothers whose children received rehabilitation services during the data collection phases. Individual interviews were conducted with 34 women who had also completed the questionnaire. Additionally, each day I observed mothers with their children in the physical therapy gym as they waited for their child’s session to begin and during their child’s therapy.

Study Participants. Mothers of children with disabilities who receive rehabilitation services at El Centro de Rehabilitacion del Neurodesarrollo in Cardenas, Cuba were the participants for this study. Mothers in this study range from 18–59 years of age. Mothers meeting the criterion of vulnerable populations, including those who are pregnant or are intellectually impaired, were excluded from the study. Mothers selected for interview in this study were requested to have a child between the ages of 1 and 18

xxxvi Rehabilitation services included medical consultation, physical therapy, occupational therapy, speech therapy, psychology, music therapy, art therapy, and dance therapy.
years of age with an identified disability. The disability could be due to physical, emotional, sensory or cognitive impairment. Previous studies that examine mothers’ experiences in relation to their child’s disability typically include mothers of children with a wide range of disabilities and conditions (Landsman, 1998; Green, 2007). Inclusion of a variety of disabling conditions allows examination of the relationship between the child’s diagnosis and maternal interpretations and actions.

Though it may be very interesting to uncover the experiential similarities and differences reported by mothers and fathers of children with disabilities, fathers were excluded from this study. Previous studies examining parenting and disability have also elected to exclude fathers, holding the position that mothers are more likely to provide direct care. Furthermore, the relatively small representation of fathers may not accurately represent those who participate in care and these fathers are unlikely to have similar experiences to fathers who are not involved (McKeever & Miller, 2004; Green, 2007). In Cuba women are the primary caregivers of children with disability and are accordingly, the most appropriate participants for this study. It is important to note that although the mothers selected for this study are distinguished from the general population of mothers of children with disability by their children’s access to rehabilitation services and some forms of support. This maternal target group reflects a diversity of educational levels, understanding of their child’s condition, participation in the rehab process and socio-

xxxvii Physical impairment—movement disorders, amputations, congenital malformations; sensory impairment—hearing or visual deficiency, sensory processing disorders/autism, Aspergers syndrome, emotional impairment-conduct disorder, depression; cognitive impairment-learning disability; mental retardation
demographic variables. Though given that this sample of women whose children have access to rehabilitation services and regularly attend therapy sessions, selection bias needs to be considered, as the experiences of the mothers in this study may be markedly different than those mothers with children with disabilities in the general population.

**Participant selection.** Survey and interview participants were recruited and identified with the assistance of the program director of El Centro. This method of recruitment is a recognized limitation of this study. But given the cultural and logistical challenges in my role as an outside American researcher coupled with the scarcity of electronic and communication resources in Cuba, this method was selected as it was the most feasible and acceptable. All women whose children received rehabilitation services during the study data collection phases were invited by the investigator to participate in the study survey. The researcher, with the assistance of El Centro staff, approached the mothers in the waiting area of the facility and invited the women to participate in the survey. Women were permitted to decline or accept the invitation without penalty or incentive. The investigator then described the survey procedures to the participant and requested her verbal consent.

Interview participants were identified for recruitment by the program director and the physical therapy supervisor. Upon identification, the research investigator spoke with each mother through an interpreter, described the interview procedures and requested verbal consent. The participants were provided with verbal and written information in Spanish that described the purpose of the study, their rights as participants and study procedures. All participants were permitted to decline or accept the invitation to
participate in the study interview without penalty or incentive. All interviewed mothers also completed the study survey prior to the interview. Mothers who were interviewed were also selected as the subjects for this study’s participant observation component. As El Centro does not have scheduled timed appointments, the mothers who were observed during the therapy sessions were the ones that showed up when I was in the gym. Thus I was able to observe a handful of mothers who were interviewed, though over several observational points. In total, one hundred women completed the study survey, thirty-four mothers participated in the interview and ten women were observed in the rehabilitation gym during their children’s therapy session. All mothers that I approached for consent to be observed in the gym with their children agreed to participate in the observation. The therapists working the children consented as well. One woman declined the invitation to be interviewed. She did not offer an explanation for her refusal. One hundred twenty surveys were distributed over the two data collection points, twenty were not returned. I was not able to discern the exact number of mothers approached to complete the survey nor the number of women asked to participate but refused as the staff that assisted in recruitment of survey participants did not keep an account. The surveys were conducted on-site in the waiting area of El Centro, with a trained El Centro staff member providing assistance to the respondents as needed.

**Subject Confidentiality**

Subject anonymity was preserved through coding procedures. Each subject was assigned a subject identification number. The study identification number does not
include any personal identifiers such as first or last names, initials, street addresses, child’s name or medical record number. The subject identification number was maintained and consistent for each component of the study including the interview, survey and participant observation. The study identification number was inserted on all study related documents such as the investigator’s observation logs and notes, interview notes and transcripts. Audiotapes obtained during the interview process were labeled and logged according to the subject identification number. Subjects’ identifying information are not audible on audiotape. All data sources including audiotapes, interview and observation notes, transcripts, and self-administered surveys are kept in a locked cabinet in the investigator’s office to ensure confidentiality.

Consent Procedures

Oral consent procedures were requested for this study. Christina Perez (2008), a sociologist who conducted her dissertation research on community medicine in Cuba, states, “Informed consent and confidentiality did not serve my participants in this study. It did not make sense to them, it did not make them feel safe, and it didn’t protect them (p. 50). Paper contracts are not part of the norm in Cuba. I became convinced that signing the contract would be a source of stress for my informants and would create a strange environment that would endanger the research process” (p. 49). Cuba’s socio-political context is grounded in a collective ideology that values integration of public and private spaces. Enforcement of written consent procedures may be viewed as a subversive
agreement and place subjects in a vulnerable position. I obtained institutional approval to conduct this study with the oral consent of study subjects.

**Study Methodology**

*Survey questionnaire.* A pen and paper study questionnaire was offered to all mothers whose children received rehabilitation services at El Centro de Rehabilitacion del Neurodesarrollo. When arriving with their children for rehab services, all mothers, were invited to participate in the survey during each data-collection point. The survey was described to the participants in Spanish and the investigator requested verbal consent. The investigator, with the assistance of the translator, provided verbal and written instructions to each participant. The interpreter earned a baccalaureate degree in English and has served as international translator for the Cuban government. She provided interpretation during every aspect of the research project including interviews, observations, discussions and meetings with Dr. Rodriguez, lunch and other social activities. Upon verbal consent, mothers were provided with the survey and a pen or pencil. The survey design was formatted in sections that elicited the following information from respondents (see Appendix D).

- Demographic data (age, social status, education level, marital status)
- Services the child and family receive and services that are needed
- Appraisal of the mother’s knowledge of their child’s disability
- Maternal caregiving roles, routines and supports
- Maternal attitudes toward disability and services at El Centro
All instructions and materials were presented in Spanish. A Cuban born interpreter translated the study questionnaire from English. The questionnaire was then back-translated to determine the integrity of the translation (Doak, Doak & Root, 1996). One-hundred completed study questionnaires were returned to the investigator. Questionnaire responses were coded into nominal or ordinal categories. A SPSS database was created and data were entered. Descriptive analysis of questionnaire data included demographic profile of the sample, frequency of responses relating to rehabilitation services, support and needs and associations between demographic information, maternal typologies, and attitudes toward rehabilitation services and disability.

Interactive Interview. Interactive interview is a qualitative method that allows the interviewer to engage in dialogue revealing the interviewer’s experiences common to the respondent. This technique is viewed as an appropriate tool for gaining insight into lived experience, particularly in groups that are often required to “tell their stories” in various medical and social contexts. In addition, interactive interviewing provides a context for a more natural pattern of communication and tends to diminish the power afforded the interviewer in one-sided conversations (Green et al., 2005). Given my position as an American-trained occupational therapist and researcher, issues of power, status and provision of socially acceptable responses often implicit in a formal interview process were of particular concern. Another concern cited in the literature and associated with the interviewer–interviewee relationship is the positioning of the interviewer as either an “insider”—those with disability or those who share the same experiences surrounding disability such as parenting a disabled child—or “outsider” interviewers who are able-
bodied or academic researchers. The literature acknowledges the advantages of being an “insider” interviewer and the challenges of an “outsider” in representing the interviewees. A key advantage of the “insider” interviewer is shared experiences and cultural co-membership with the interviewee. On the other hand, the academic discourse illustrates the benefits of an “outsider” in offering an alternative perspective that is able to elucidate aspects of the phenomenon not viewed from the inside (Humphrey, 2000).

My position in this research study was as an “informed outsider.” Although I did not share the experiences of the mothers with children with disabilities, as a child with juvenile rheumatoid arthritis, my participation in educational and social environments were limited due to my physical impairments. Moreover, in my role as a pediatric occupational therapist, I acquired first-hand knowledge of a variety of challenges and successes experienced by children with disabilities and their families. An additional concern that I had prior to the interview process was my status as a citizen of the United States and non-native language speaker. Even though I enjoy a long-term relationship, spanning over 7 years, with El Centro de Rehabilitacion y Neurodesarrollo in Cardenas and have had the opportunity on several occasions to interact with and informally interview staff and families without challenge, I do recognize my non-Cuban status as a limitation of this study. Going into this study, I was aware that my status as a foreigner could present some cross-cultural challenges such as understanding and interpretation of cultural nuances, modes of communication, my own ethnocentrism, and

xxxviii I have chosen the term informed outsider as, although I am not Cuban, nor share co-membership with the group that I am studying, I have knowledge and firsthand experience surrounding issues of disability and Cuban culture and structures.
participant trust and openness during the interview process. These experiences in combination with the cross-cultural context of this study provided support for my selection of interactive interviewing as an appropriate research technique.

All interviews were conducted in a consultation room located on the first floor of El Centro. My initial plan was to preferably interview all or many of the subjects in their homes or at a private space in the community. However, this expectation was impractical as El Centro did not have an effective method to schedule appointments and many mothers lived quite a distance from the rehabilitation site. For this reason, the study interviews took place before or after a scheduled rehabilitation appointment.

All interviews were conducted in Spanish. A state certified interpreter was present during all research activities including informal exchanges with staff and mothers, survey administration, observation of rehabilitation practices and formal discussions with staff and families. Prior to initiation of each interview subjects were requested to assert their verbal consent to participate in the interview. The consent form text was read aloud to each participant in Spanish by the investigator as the participant followed along with a written copy of the consent form that presented the objectives of the study and the research procedures.

An interview script was used to guide the interview process (see Appendix C). The length of interviews with mothers ranged from 20–90 minutes, with most interviews lasting about 55 minutes. The interview script was written in Spanish and English. Based on the subject’s response to a particular question I alternated the sequence of questions, added follow up questions as needed and eliminated questions that were viewed as not
relevant to or potentially emotionally difficult for the subject. The script was based on a conceptual framework that reflects contributions of the literature and represents inquiry at structural, institutional and individual levels. The interactive interview took on a narrative, dialogical approach with questions being open-ended and thematic in nature. All interviews were audio-taped and then transcribed by the researcher. I also documented participants’ responses on the interview script. A sample of 34 women participated in the interview. Based on interview responses I categorized the interviewed mothers into typology categories that were reflected in how they approached their children’s disabilities and navigated institutional systems. The typology categories included the provincial mother, the community mother, the cosmopolitan mother and the remote mother. In order to evaluate the validity of my typology categories and placements of the interview sample, two graduate students were enlisted to review interview transcripts and locate mothers into categories according to typology criteria. Agreement between my typology placements and the graduate students was achieved. These categories are further discussed in Chapter Seven.

Analysis of interview data were coded according to themes that emerged during the interview process. Kvale’s (1996) method of categorization and structuring of meaning through informants’ narratives was employed to gain understanding of the relationship between socio-cultural environment and the actions that mothers of children with disability take in managing the care of their child. Thematic categories were entered into the SPSS database. Data analysis included cross-tabulation evaluation of associations between mothers’ typology and interview responses.
Participant observation. Participant observation is a method in which the researcher takes part in the daily activities and interactions of a group of people in an effort to learn the explicit and tacit aspects of their life routines and their culture (DeWalt & DeWalt, 2002). Each day I observed the environment at El Centro with a focus on daily routines, interactions between families and staff and institutional processes. I had open access to all the treatment spaces and offices located within El Centro. The consultation room in which the study interviews were conducted was adjacent to the general waiting room and provided easy access for general observations of the rhythm, pace, social interactions and institutional procedures as families waited for medical and therapy appointments. With the consent of mothers who were interviewed and permission of the therapy staff, I conducted the participant observation portion of the study in the physical therapy gym.

The staff and some families already knew me in my previous role as an educator and therapist at El Centro and were comfortable with my role as an observer in the clinic. Within this context, I introduced myself as a researcher and therapist observing the gym in an effort to better understand how rehabilitation services are delivered in Cuba. At times, the therapists would request my assistance during the therapy session and mothers would engage me in conversation. The focus of my observation was on mother-therapist interactions. I developed a form that recorded my observations of the ecological and social environment. The form included items such as mother or therapist initiates social greeting, initiates entry into therapy session, offers suggestion (see Appendix G). Observation data were recorded and coded for frequency of identified interactions.
Limitations

Due to the qualitative and cross-cultural aspects of this proposed study, potential limitations were of concern. The study sample was a sample of convenience. Thus, the sample is not random, nor are the findings generalizable. On the other hand, this study provided rich and textured insight into the experience of disability through the lens of caregivers in this particular socio-cultural setting. Concerns including styles of communication, power relations between the researcher and the participants and participants’ willingness to disclose personal experiences and attitudes may have limited the reliability of self-reported information. Efforts were made to garner participant’s trust, create a safe environment for research activities and assure the confidentiality of all participants. Participant and group member checks were performed to monitor the influence of my cultural foregrounding during the data collection and analysis process. I recorded my reflections in a journal to assist with processing of cross-cultural interactions, expectations and roles. Though the study allows some within-group comparison between the interviewed and non-interviewed samples and within the interviewed group typologies, the study is effectively a one-group design with its attendant problems.

Cultural and Organizational Challenges

Situating this study in Cuba presented a variety of cultural and organizational challenges. The first issue I was confronted with was the process of obtaining approval from the state to conduct my research at El Centro. Initially the process, as it was
described, seemed to be rather straightforward—approval from El Centro, then on to the provincial Ministry of Health and finally review by the national health ministry. In reality the process was circuitous as organizations and ministries struggled with the allocation of responsibility. My efforts to facilitate the process were limited by inability to travel to Cuba due to US travel restrictions. Cultural and organizational aspects of electronic communication also influenced the process. Emails sent to Cuba were sometimes not acknowledged due to infrastructure issues and cultural patterns of technological communication. In other words, Cubans tend not to check and respond to their email as instantaneously or regularly as Americans do. With the exception of my heightened anxiety and feelings of impending doom during the research approval process, it all worked out in the end and I gained better understanding of the interactions and workings between institutional structures.

Based on my previous experiences at El Centro, I was familiar with the social and cultural context of the setting, its organizational arrangements, daily routines and several of the cultural scripts adopted by staff and parents. Nonetheless, the implementation of this research project brought to the surface various organizational and cultural considerations that needed to be acknowledged and taken into account during the research process. Appointment scheduling and statistics maintenance were managed in a somewhat informal manner. Families whose children receive services at El Centro are often scheduled to come to therapy every day although at no specific time. The staff

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US travel restrictions limit professional travel to research only. As I did not yet have approval from Cuba or institutional review boards I was not conducting research and therefore could not go legally.
schedules the daily sessions with the rationale that most families will miss appointments, therefore if appointments are scheduled for every day the child will come in at least a few times during the week. Many of the families do come in a few times a week, but the day or time of day they will arrive is not defined or certain. This method of scheduling made it difficult from a research perspective to schedule interviews and observations. Additionally, depending on their time of arrival and the reliability of transportation, the mothers and children may wait a long time to be called in for a therapy session or not know when the session will start, thus compromising their ability to participate in an interview.

It was also difficult to get a good sense of El Centro’s total census, as record keeping is fairly limited in scope. El Centro captures the monthly number of physical therapy sessions and then the monthly number of all other services (i.e., occupational therapy, medical consultations, psychology, etc.). The number of individual visits per month or number of children receiving services each month is not calculated. Hence it is unclear how representative this study’s sample is of El Centro’s population. Report by the physical therapy supervisor estimated that each therapist treated an average of 10 children daily. In February 2009\(^{xl}\) there was total of 806 physical therapy visits for the month, 201 visits per week and about 40 visits per day. As all children receive therapy more than one day a week, I would suspect that within a one week time frame if each child attends therapy at least twice a week, the physical therapy population is around 100–125 children. Other rehabilitation services, including psychology, speech and occupational

\(^{xl}\) Statistics provided by El Centro’s secretary.
therapy, documented a total of 180 visits during the month of February 2009, with an average of 9 visits daily.

The main cultural challenge that presented during this study was the issue of public versus private space and information. The blurring of public and private played a role in subject recruitment and interviewing. Cuba is a public society. Extended families live in close quarters, physicians visit patients in their homes, individuals gather in outdoor spaces to discuss politics and sports and mothers at El Centro huddled together in the waiting room and openly shared their personal stories. Word of mouth, peer encouragement, expectations that everyone was to be included in all activities and possibly the desire of collective approval enlisted the interest of all mothers in the study questionnaire, thus interfering with a solid methodical approach to recruitment. The consultation room in which the interviews took place had two ten foot high windows with open shutters that provided community members who walked by the opportunity to peek in, ask questions and start a conversation with whomever was in the room, including interviewees. During one interview the cab driver that transported the mother I was interviewing and the two families that shared the taxi with her patiently gazed through the large window observing the interview experience. When I brought up the issue of privacy, the mother seemed a bit surprised and expressed her approval of the group being present. Although the door to the room was closed during all interviews, staff frequently interrupted to ask questions, drop off completed questionnaires, freely offer information relating to the interviewee or just to say hello. All mothers appeared comfortable with the
interruptions and public exchange of personal information, often adding their own comments to their narrative.

**The Study Sample**

The study sample consists of one hundred women who have a child with disability and receive rehabilitation services at El Centro de Rehabilitacion y Neurodesarrollo in Cardenas, Cuba. Each of these 100 women completed the research questionnaire. Thirty-four of the 100 women in the sample participated in the study interview; this group of women were recruited with the assistance of staff. Staff was instructed to identify women for interviews whose children received multiple services and were not included in the early intervention program. Ten of the thirty-four mothers who were interviewed were also observed in the physical therapy gym prior to and during their child’s rehabilitation session.

The full sample of 100 mothers ranged in age from 18–59 years with 35 percent of the women between the ages of 18 and 29 years. Fifty percent of the women surveyed work outside of the home. The majority of women report being married, although the differences between marriage and consensual unions in Cuba are not well defined. Seventeen percent of the sample identified as divorced. Over 60 percent of the women reported having one child. The sample is stratified along educational levels with 21 percent of mothers achieving a university degree, 37 percent completing pre-university and 27 percent finishing a polytechnicalxli program. A little under two thirds of the vocational training program

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xli vocational training program

118
children of the women in the general sample were between one and five years of age and were identified as having a neurological or developmental condition.

Table 4.1

*Demographic profile: Survey demographic responses*

<table>
<thead>
<tr>
<th>Mother’s age</th>
<th>Sample Size</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>18–29</td>
<td>35</td>
<td>35%</td>
</tr>
<tr>
<td>30–39</td>
<td>33</td>
<td>33%</td>
</tr>
<tr>
<td>40–59</td>
<td>9</td>
<td>9%</td>
</tr>
<tr>
<td>No report</td>
<td>23</td>
<td>23%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Maternal education level</th>
<th>Sample Size</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary school</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Secondary school</td>
<td>7</td>
<td>7%</td>
</tr>
<tr>
<td>Polytechnical</td>
<td>27</td>
<td>27%</td>
</tr>
<tr>
<td>Pre-university</td>
<td>37</td>
<td>37%</td>
</tr>
<tr>
<td>University</td>
<td>21</td>
<td>21%</td>
</tr>
<tr>
<td>No report</td>
<td>6</td>
<td>6%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mother’s marital status</th>
<th>Sample Size</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>65</td>
<td>65%</td>
</tr>
<tr>
<td>Divorced</td>
<td>17</td>
<td>17%</td>
</tr>
</tbody>
</table>

(continued)

| Single | 7 | 7% |

119
<table>
<thead>
<tr>
<th>Consensual union/other</th>
<th>8</th>
<th>8%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No report</td>
<td>6</td>
<td>6%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other family status</th>
<th>Sample Size</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother works outside of home</td>
<td>50</td>
<td>50%</td>
</tr>
<tr>
<td>Family lives in Cardenas</td>
<td>47</td>
<td>47%</td>
</tr>
<tr>
<td>Only one child in family</td>
<td>63</td>
<td>63%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child’s age</th>
<th>Sample Size</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 year</td>
<td>24</td>
<td>24%</td>
</tr>
<tr>
<td>1–2 years</td>
<td>32</td>
<td>32%</td>
</tr>
<tr>
<td>3–5 years</td>
<td>33</td>
<td>33%</td>
</tr>
<tr>
<td>6–11 years</td>
<td>11</td>
<td>11%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child’s diagnosis</th>
<th>Sample Size</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental</td>
<td>32</td>
<td>32%</td>
</tr>
<tr>
<td>Neurological</td>
<td>30</td>
<td>30%</td>
</tr>
<tr>
<td>Orthopedic</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Congenital</td>
<td>5</td>
<td>5%</td>
</tr>
<tr>
<td>Behavioral</td>
<td>17</td>
<td>17%</td>
</tr>
<tr>
<td>No report</td>
<td>15</td>
<td>15%</td>
</tr>
</tbody>
</table>

*Note. N=100*

Sixty-six percent of women reported that they had primary responsibility for their child and an impressive ninety-one percent of mothers indicated that family members help with the care of their child.
Table 4.2

*Family support—Survey responses to maternal perceptions of family support in the care of their children with disabilities*

<table>
<thead>
<tr>
<th>Survey question</th>
<th>Most frequent response</th>
<th>Percent of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person primarily responsible for the home</td>
<td>Mother</td>
<td>65%</td>
</tr>
<tr>
<td>Person primarily responsible for the child</td>
<td>Mother</td>
<td>60%</td>
</tr>
<tr>
<td>Family helps with care of child</td>
<td>Yes</td>
<td>91%</td>
</tr>
<tr>
<td>Family member that primarily helps with child</td>
<td>Collective family</td>
<td>58%</td>
</tr>
</tbody>
</table>

*Note.* N=100

The most utilized service at El Centro is medical consultation, followed by physical therapy, speech therapy, dental care and occupational therapy (see Table 4.3).

Table 4.3

*Services received—Survey responses to services child and family received at El Centro*

<table>
<thead>
<tr>
<th>Service received</th>
<th>Percent receiving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical care</td>
<td>68%</td>
</tr>
<tr>
<td>Physical therapy</td>
<td>59%</td>
</tr>
<tr>
<td>Speech therapy</td>
<td>39%</td>
</tr>
<tr>
<td>Dental care</td>
<td>37%</td>
</tr>
<tr>
<td>Table 4.3 (continued)</td>
<td></td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>31%</td>
</tr>
</tbody>
</table>

121
<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dance therapy</td>
<td>23%</td>
</tr>
<tr>
<td>Parent group</td>
<td>15%</td>
</tr>
<tr>
<td>Music therapy</td>
<td>14%</td>
</tr>
<tr>
<td>Child counseling</td>
<td>7%</td>
</tr>
<tr>
<td>Art therapy</td>
<td>5%</td>
</tr>
</tbody>
</table>

*Note. N=100*

When survey respondents were asked to identify services that are not available or underutilized at El Centro, more than half of the respondents suggested transportation services. Classes for parents and equipment for children were ranked second. Help in the house, counseling for mothers and education for children about disability were recommended by more than a third of the sample. (see Table 4.4)

Mothers’ evaluation of El Centro’s provision of services and the community’s attitudes toward disability indicated that over 80 percent of respondents always felt comfortable asking the staff questions, always felt included in the therapy session and always received support from the staff in understanding their child’s condition. At the same time, just over half of the sample always felt that the community had a positive attitude toward disability and less than 40 percent of mothers always felt that they could make a difference in changing attitudes (see Table 4.5).
Table 4.4

*Services Suggested by Mothers—Maternal survey responses indicating services needed by their children and families that are not offered at El Centro or need to be enhanced*

<table>
<thead>
<tr>
<th>Suggested service</th>
<th>Percent suggesting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation</td>
<td>56%</td>
</tr>
<tr>
<td>Classes for parents</td>
<td>43%</td>
</tr>
<tr>
<td>Equipment for children</td>
<td>42%</td>
</tr>
<tr>
<td>Education for children about disability</td>
<td>37%</td>
</tr>
<tr>
<td>Help in the house</td>
<td>37%</td>
</tr>
<tr>
<td>Counseling for mothers</td>
<td>35%</td>
</tr>
<tr>
<td>Education for mothers</td>
<td>27%</td>
</tr>
<tr>
<td>More therapy</td>
<td>26%</td>
</tr>
<tr>
<td>Education for siblings</td>
<td>14%</td>
</tr>
</tbody>
</table>

*Note.* N=100

Table 4.5

*Mothers’ perceptions of rehab services and attitudes toward disability—Percentage of mothers who responded always to each statement. Other choices included most of the time or no.*

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percentage responding “always”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mothers are comfortable asking staff questions</td>
<td>89%</td>
</tr>
<tr>
<td>Mother is included in therapy session</td>
<td>82%</td>
</tr>
<tr>
<td>Staff helps mothers understand child’s condition</td>
<td>80%</td>
</tr>
</tbody>
</table>
The staff respects mothers’ opinions 78%
Mother can make a difference in child’s progress 66%
Center offers parent education 64%
Center provides support services for mother 62%
Center offers needed services for child 59%
The community has a positive attitude toward disability 54%
Mother can make a difference in changing attitudes 36%

*Note. N=100*

Mothers who were interviewed in this study provide a rich diversity of educational level, age, geographical location, and experience in taking care of their child. Each mother’s story is unique, yet common themes related to mothering, making sense of their child’s condition and how they negotiate their particular socio-cultural environment emerged during the interview process and ecological observations. The following chapters provide an account of the experiences, strategies and attitudes presented by mothers who care for their children with disabilities in Cardenas, Cuba.
CHAPTER 5
MAKING SENSE OF THE DIAGNOSIS: IDENTIFICATION AND UNDERSTANDING

“I noticed that his right foot turned in when he started walking.” —Elsa

Elsa describes her two and half year old son who receives rehabilitation services at Cardenas’ El Centro de Rehabilitacion y Neurodesarrollo as “very happy all the time. He likes to dance and sing.” Elsa noticed that when her son was about 18 months old, he had started to walk his right foot was turned in. She brought her son to the family doctor who then referred her to a neurologist in Havana. In Havana, her son was diagnosed with a neurological problem that resulted in weakness in his right arm and leg. The doctor in Havana told Elsa that her son’s problem began when she was pregnant. Her son “had a lot of distress and he was not making progress in motor development.” When Elsa’s son received his diagnosis, he was sent to rehabilitation at El Centro.

Elsa states that at first she was frightened when she learned of her son’s diagnosis, she was “really scared with the whole problem.” The doctor told her that maybe with rehabilitation “the child would do better.” Elsa’s son now walks, does things by himself, though “it is not so easy for him but he can do it.” The family is trying to get Elsa’s son to walk properly. Now a year after her child’s diagnosis Elsa reports that she feels
different and she is “more calm” as she can see her son’s progress. Elsa says, “He is golden. I know that he is not going to walk one hundred percent, but he can get better.”

Elsa explains her son’s condition to family and friends as having difficulty walking properly. When asked how she understands or explains her son’s condition to herself she revisits her pregnancy. “My pregnancy was normal. I had a Caesarean section.” And then she reflects, “I don’t explain the child. I try to make progress for the child, and the family has helped with that.” Elsa’s advice to other women who have a child with a disability is “to give a lot of love, to be patient and do not lose your hope.”

Elsa’s narrative reveals not only the emotional aspects of women’s experiences when their children are identified with a disabling condition, but also draws attention to the structural and institutional mechanisms that shape the process of assigning a diagnosis and communicating information to aid mothers’ understanding of their children’s conditions. The timeliness of the child’s diagnosis, the coordination and location of medical and rehabilitation services, physicians’ communication with each other, and the words used in explaining sophisticated medical terms come together to form women’s narratives and perceptions of their children’s conditions, challenges and abilities. Elsa’s narrative is also similar to other mothers and doctors’ focus on walking and getting better.

This is the first of three chapters that report the findings gathered from the study interviews and surveys. Elsa’s narrative will open each of the three results chapters to provide a sense of coherence of the interview process. The organization of this study’s results is driven by the empirical data, positioning the most salient and meaningful
findings in the forefront. During the interview process I was struck by the depth and
detail of the interviewees’ stories related to the identification of their children’s
diagnosis. The experience of being a mother of a child with disability typically begins
with the notice of a possible problem, identification and labeling of the problem,
response, making sense of it, explaining it to others and seeking or sharing advice.

One of my intentions during this study was to convey my genuine interest in the
daily experiences of the mothers and their families and to avoid framing the interview
process as a clinical or medicalized dialogue. Toward that end, I began each interview
encounter by asking the mothers to tell me about their family, their experiences as
mothers and their child who receives services at El Centro. Several of the participants
responded to this request with a description of their child’s diagnosis. This finding is not
unusual or specific to the context of this study. Kearney and Griffin (2001) found that
although parents of children with disabilities are often invited to tell their stories from
their own perspectives, they invariably begin with either the birth of the child or the
identification of their child’s impairment.

It is important to note that the 34 mothers in the face-to-face interview sample
were invited by El Centro staff to participate in this study. Hence, their experiences and
viewpoints are not representative of the larger sample of mothers who were surveyed nor
do they capture the viewpoints of women who chose not to participate in the study and
those who upon referral to El Centro decided not to bring their children for therapy.
Selection bias and issues of external validity are therefore a concern. In comparison to
mothers who care for children with disabilities and do not have access to rehabilitation
services, the participants in this study may represent a more favorable view of disability services, demonstrate a better understanding of their children’s condition or be more comfortable with professional interactions and community attitudes. On the other hand, in contrast to the non-interviewed mothers surveyed, the women who were interviewed in this study tend to care for older children with more severe disability. As a result, their narratives may reflect more challenges and difficulties in the care of their children.

When asked to describe their children, the interviewed mothers approached this request from distinct perspectives. While other studies have found that mothers begin their story with the diagnosis, this was not always the case for mothers in this study. A portion of the women began the introduction of their children with disability by presenting their particular attributes, interests or characteristics. Belkis captured the spirit of her daughter noting that “she is a hurricane, she is spontaneous, smart, very active.” Marta listed the activities her daughter prefers, “she loves to swim, she knows her characters on TV, she likes ice cream.” Two mothers commented on their sons’ activity level and social relatedness. Elsa offered “my son is very active, he says hello to everyone.” Fatima proudly stated “my son is very friendly, good with small kids.” Other mothers described their children as quiet, mischievous, very sweet, caring and good with younger children. Rosario adds another dimension in her response noting her relationship with her son and her son’s social location within the community, “My son is close to me, he plays with other kids, he is accepted.” These responses may be reflective of the mothers’ affirmation of their child’s personhood and their experiences of motherhood, as they enfold the “normalcy” of their child into their reconfigured maternal narrative or it
may also suggest a counter-narrative that rejects notions of the medical discourse (Fisher & Goodley, 2007; Landsman, 1998).

Yet most of the mothers began their description of their children by either identifying their children’s diagnoses or referencing their children’s disabilities.

“His diagnosis is psychomotor.” —Mayra

“When she was born I was not expecting her to be Down Syndrome, it was a shock.” —Juanita

“At five-years-old he passed out, he had a brain infarct.” —Theresa

“When he was born he had five problems with his heart, he doesn’t walk, he doesn’t speak.” —Alina

“It is hard for him to do his homework.” —Miriam

“The child was nine-months old, wouldn’t walk, could not stand.” —Luz

“Child had fast movement in eyes and legs.” —Thelma

Mothers who present their children’s disabilities or diagnoses as their introduction of their children could certainly be influenced by the clinical environment in which the interviews took place or by the dominant medical discourse that surrounds disability in Cuba. However, this approach of initially describing the child in reference to his condition not only underscores the significant meaning attached to having a child with disability, but also brings attention to the identification of a child’s condition as a major marker in the mothers’ personal narratives. Kearney and Griffin (2001) posited that parents’ revisiting of the start of their journey with their children with special needs is a somewhat therapeutic step that allows the parents to focus and participate in the interview
process. This finding may help in understanding why some mothers in this study framed the interview questions and dialogue with their experience relating to the identification and naming of their children’s disabilities.

Nevertheless, diagnostic or impairment-based introduction of their children can also point to mothers’ challenges in acknowledging and reconciling their children’s personhood. Denial of personhood or full social recognition of a child with disability is not uncommon, particularly when children are first diagnosed (Landsman, 2003). Rejection of a disabled child’s personhood may be reflected in depersonalized language or emotional distance, and in turn provide mothers with time and space as they reconstruct their notions of motherhood and their narratives about their children. Landsman (1998) puts forward the notion that a child’s capacity to give and receive love appears to be a defining feature of mothers’ ability to see their children’s humanity. As previously noted in this study, maternal love is an important factor in women’s choices to have children and to engage in mothering practices (Hays, 1994). The literature suggests that rejection of a disabled child’s personhood may be influenced by the severity of the child’s condition, lack of knowledge, cultural expectations and the assignment of blame to the mother (Landsman, 1998, Landsman, 2003; McKeever & Miller, 2004; Shapiro & Tittle, 1990).

Recognition of the personhood of a child with disability can be a complicated process as the child is alternately and sometimes simultaneously viewed as a patient, a fragile or impaired individual or “full” human being (Goodley & Tregaskis, 2006). Landsman (1998) contends that mothers reconstruct the personhood of their disabled
child later in the child’s life as they become more knowledgeable about their child’s condition and are possibly transformed by their mothering experiences. Personhood is contingent upon social recognition and hence reflects the social value of the individual to the society (Morgan, 1996 as cited in Landsman, 2003). In a collective, paternalist society, such as Cuba, the presence of disability can be particularly tricky as those who are disabled are often viewed as needing care and protection with attendant exclusion from responsibilities. Although the visible presentation of disability marks the child with disability as *other*, it is the naming of the condition that jeopardizes the perceived humanity of the child as it alters women’s narratives of motherhood. The diagnosis is thus the outcome of noticing symptoms and labeling the condition. Social power is inherent in the diagnostic ritual. The diagnosis legitimizes the condition, links the physician to the child and parent, explains the problem, directs practice and confers social approval on particular, culturally agreed upon sick roles. The naming of the condition could lead to a host of possibilities—the potential of the condition improving or progressing. The trajectory of disability, however, is often viewed as being a static condition without chances of improving. (Rosenberg, 2002). As a result, if disability is constructed as an undesirable condition within a specific culture, the social value of a child with disability is diminished, compromising full personhood and the assignment of stigma onto the child and often the mother. Peeling away the layers that surround the process of identifying the child’s diagnosis may provide additional insight into the far-reaching impact of disability on the daily lives and narratives of women who mother children with disabilities.
Noticing and identifying the problem

Who notices when a child is lagging behind his peers developmentally, has difficulty with moving, talking or understanding? Often it is the child’s mother. At times family members, childcare workers and teachers become aware of a child’s difficulties and share their perceptions with the mother. Physicians identify concerns surrounding a child’s health in a variety of contexts including prenatal care, the birth process, well-baby visits and within specialty practices. Twenty-nine percent or 10 of the 34 women who were interviewed in this study indicated that a physician notified them of their child’s condition at the time of birth. The children of these mothers presented with a congenital abnormality or a significant neurological event that occurred prenatally or during delivery of the child.

Juliana shared her experience of her child’s birth. “When she was born no oxygen was going to her brain for 30 minutes. It was a normal delivery, but her birth was delayed. She did not progress. At 11 days, she was in therapy, then she had to go to Havana. Eight months later she came to El Centro.” Alina stated, “I found out about the condition immediately when he was born. His heart was very damaged. The doctors did not expect him to survive.” Both of the women in this study who mother a child with Down Syndrome were notified of their child’s condition around their time of birth. Although one mother was informed of her daughter’s condition by the delivery physician, the other mother found out about her child’s diagnosis on her own. “Because I have diabetes, I did not see the baby right away. The doctors did not tell me because of my
diabetes. I found out when I went to see the baby. Then I knew because I had seen children with Down Syndrome on the street.”

Most of the women who were interviewed in this study, 53 percent of the sample, reported that they initially identified a problem with their child and then sought services. Elena observed that her son was delayed in his language skills and took him to a speech therapist. Another mother noticed that her son was “floppy” and could not sit up at four months. Luz noted her son’s difficulty at an early age though her family doctor thought her son was okay. “When he was one-year-old he would not walk. He was rigid.” Three of the mothers within this group indicated that, though they noticed that their child had a problem early on and they sought and received services for their child, the assignment of an official diagnosis was delayed up to two years after the parent’s observation. This finding, however, is not unusual as often the full presentation of the child’s disability is manifested as development occurs. Additionally, physicians may delay identification of a diagnosis, particularly with children with neurological or developmental markers, until the condition is known for certain (McLaughlin, 2005). Even though a delay in identification of a child’s diagnosis is on occasion necessary, the anxiety imposed by this process as parents struggle with the tensions of uncertainty cannot be overstated.

The children of six mothers, 18 percent of the interviewees, received a delayed diagnosis ranging between three months to two years after birth. Marta’s narrative provides a compelling example of how the intersection of institutions, material resources and individual factors led to identifying a child with a disabling condition.
It was my first child. I was very young. The first time I arrived at the doctor was at day seven. They didn’t do much there because the doctor didn’t have transportation. They did not realize that she had a problem. I went once a month to the doctor. But he did not find anything. At four months a friend of mine said that her child was a month younger than mine and that she did more things than Mercedes. So I brought my child here to the center. They gave me a consultation. There had to be some tests. In Cardenas they do not have the equipment so I had to go to Havana. But I could not do it because Mercedes has an infection of the ear. Sometimes she could not come because of asthma. When she was 6 months old she had hypotonia, had a head lag. When she was a year and a half she was able to sit well. When she had 2 years she finally had the tests. She has brain paralysis, atrophy of the brain. (Marta)

Over recent years the Cuban health care system has begun to decentralize health services through the expansion of polyclinics, addition of specialty practice physicians and enhanced coordination between the polyclinic and family doctors. Still, the women in this study identified gaps in the referral process to rehabilitation services, transportation problems getting to appointments in the polyclinics or specialty hospitals, difficulties setting up appointments in Havana and little communication between the specialists in Havana and the rehab center in Cardenas. A health professional informant acknowledged the challenges cited by the mothers and added that at times the specialists in Havana and physicians in Cardenas do not come to the same diagnosis for a child.

Families were unable to attend specialty appointments in Havana due to the prohibitive costs of taxi and lodging and limited access to Cuban convertible pesos or US dollars. A public bus from Cardenas travels to Havana on certain days of the week,

Mercedes is a pseudonym for the child.

Hypotonia is low or floppy muscle tone. It can indicate a neurological condition.
though the schedule often does not match the dates of scheduled appointments and the bus cannot accommodate children with significant disabilities or behavioral concerns. Communication between medical specialists in Havana and family physicians in Cardenas are constrained by the nation’s telecommunications infrastructure. Personal and business telephones are limited and access to email is inconsistent. Material conditions and undefined processes and operational procedures place a substantial burden on the families of children with disabilities as they negotiate systems that will lead them to the assignment or labeling of their children’s diagnoses. The particular institutional barriers that obstruct families during the diagnostic process are no more or less a barrier in Cuba than in other sociocultural contexts. McLaughlin (2005) in her review of the social practices that guide assignment of a diagnosis of childhood disabilities in the United Kingdom found that the process of informing parents of their children’s disability is marred by organizational delays and lack of coordination. Families often receive deficient information and guidance about the diagnosis, and the delivery of the information is unsympathetic and presented in a cold manner. Once the child’s impairments are labeled as a medical diagnosis the process of understanding the meaning and implications of the diagnosis begins.

**Naming the problem and understanding the diagnosis**

Labeling a medical condition can be viewed as bringing legitimacy to an illness and at the same time support dividing practices that foster notions of normal and abnormal, healthy and sick, able and disabled. A diagnosis of disability often locates
individuals on the margins of society as they are excluded from full participation in health, economic and educational environments. While disease may be a biological construct, sickness and disability are social states. As a social entity, disability shapes institutional decisions, structures and legitimizes practice patterns and reconfigures the lives of individuals with disabilities and those caring for them (Rosenberg, 2002). When a disabling condition is labeled and legitimized as a medical diagnosis, the behaviors of the individual with disability and their caregiver can change. Understandings of the assigned label and interactions and judgments concerning the disability are both context specific and context determined. The social context may steer caregivers to protect the child with disability, fight for the child’s services and inclusion, adopt the role of health care paraprofessional, or detach from the child. Freidson (1974, as cited in Cockerham, 2004) organized the labeling of illness into three categories: 1) conditional legitimacy where individuals are temporarily excused from typical obligations, 2) unconditional legitimacy which is assigned to individuals whose sickness is viewed as hopeless and thus permanently excludes them from normal obligations, and 3) illegitimacy where individuals who are not technically responsible for their condition, such as those with disability, are exempt from some typical obligations, while they are allotted a few privileges and at the same time are assigned the handicap of stigma.

Friedson’s description of the unconditional legitimate illness state, though general in principle, may be considered in relation to Cuba’s social arrangement of releasing mothers of children labeled with a disability diagnosis from employment and awarding the mothers financial support to care for their children. Thus, in effect the assignment of
medical diagnosis to the socially constructed experience of disability provides a secondary benefit to children and their caregivers. Even though labeling of a particular medical condition is useful in promoting shared knowledge and clarity, the vignettes presented below show that the process of assigning a diagnosis can be overwhelming and may not illuminate caregivers understanding of their children’s condition.

I record everything. Julio Diaz is a therapy hospital in Havana. My husband and I were there for several days. My husband’s aunt has been there as a patient and we were able to take the boy there. Now he is going to the orthopedic hospital in Havana. I want the boy to see a specialist. The child was six months. He would not sit, not crawl. When he was nine months old we would sit him and he would just fall back. When he was one-year-old he could not walk, he was rigid. So the family doctor in Limonar thought he was okay. When children are one month of age I think they should be seen by a physiatrist, so that kids can be fixed. I am not over it. I am not very comfortable. If you see him you see that he is okay. But we are not satisfied. He has a leg that is still not moving properly. But we will not stop until we get it fixed. His diagnosis is quadraparesis. I did not have good understanding of the diagnosis at the time. I was not convinced with his diagnosis at that time. So I had him take a lot of tests. So when we had these tests the neurologists sat down with me and explained it again. It is a static condition. So we have to move on. (Luz)

I found out at three months after birth. I realized it. He had a convulsion during breastfeeding. They were afraid there was a problem with the heart. We went to Matanzas and then to Havana. He had a MRI. He had a lot of tests and the diagnosis was given. The process took three months. We went back to Havana at six months, at the time they did not have the tests here. What they gave me [the diagnosis] was not easy because I could not understand, they helped me a lot. They explained how I could actually do the treatment when he had a convulsion. They showed me everything. He has low muscle tone. I did not know anything. He went to physical therapy. He made no progress. I was at the center from morning to afternoon. I bring lunch. After a different medication it was only then I saw progress. (Carmen)

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xlv physician who specializes in rehabilitation medicine

xlv Matanzas is the capital of the province in which Cardenas is located
When he was five-years-old he was playing in the house with a friend. His father was in the house. I was working at the airport at that time. Child was sitting on the steps. He fell to the floor. He could not get up. It was like he had a head injury. He had an accident or he passed out. We went to the hospital. After three days the doctor could not explain what happened. He had a MRI. He had a brain infarct. He was in a coma when he was in the hospital. Third day brought in a doctor from Havana. Did another MRI. Confirmed the brain infarct. I was so nervous I don’t remember the exact time he was diagnosed. Then he went to a different ward in the hospital. He was having a seizure. In Havana I was treated very nice. They did not figure out the cause. They explained to me it is not common what happened, but they did not know the cause. After many days they gave him a diagnosis, abscess of the middle cerebral artery. Severe brain hypopfusion. Lack of oxygen to the brain. It started as a congenital problem. Now when he sleeps he is having seizures. He was sent to Havana for rehabilitation. Began coming to this center for six months. (Theresa)

These three vignettes are representative of the range of events and understandings mothers experienced during the process of assigning a diagnosis to their children. Uncertainty with the diagnosis, lack of knowledge and understanding of medical terms, and anxiety surrounding the process come together to form narratives that are at the same time deeply internalized and skimming the surface ready to be shared with minimal invitation. The themes woven in these stories represent aspects of Gilbert Foley and J. D. Hochman’s (2006) work on how parents reconcile the birth of their child with disability with their prenatal expectations of the child “hoped for.” These themes include loss of the child hoped for by the mothers, disbelief and disorientation, search for a different diagnosis, acknowledgment and search for meaning, and development of a personal mythology or reconstructed internal representation of their child.

Luz’s description of the process of naming her son’s impairment reveals her search for both certainty and an alternative diagnosis that is fixable. Through family
connections, Luz sought experts in the field, questioned the diagnosis, pushed for additional testing and yet still had difficulty understanding the meaning and impact of her child’s condition. Luz’s search could be viewed as denial of the diagnosis or enactment of her agency within her situated context. It was after she exhausted her resources that she was able to have a sense of her son’s diagnosis and to acknowledge his condition. Carmen’s story points to the impact of the health care system and material conditions on the timeliness of the child’s diagnosis and her understanding of her son’s condition. Complicated medical information presented a challenge to Carmen’s understanding of the full breadth of her child’s diagnosis of brain paralysis, keeping her in a state of disequilibrium. Theresa’s experience is embedded in the emotional trauma, helplessness and uncertainty during the diagnostic process as she grappled with the loss of her dreams for her child.

The study questionnaire solicited information regarding the children’s diagnoses. Of the women who agreed to participate in the study survey 85 percent offered their child’s diagnosis when asked if the child has been identified with a particular diagnosis or condition. Thirty-two women reported their children’s diagnosis as developmental delay, 30 mothers indicated that their children have a neurological disability, 17 children were diagnosed as having a behavioral condition, five children were diagnosed with a congenital syndrome and one child had an orthopedic disability. During the study interview the vast majority of women provided their child’s diagnosis and demonstrated a basic understanding of their child’s condition. When asked to tell me how they understand their child’s diagnosis, about a third of the mothers articulated keen
understanding of their child’s condition and its implications, “he has dyspraxia in his arm and leg on the left side,” “the diagnosis is neurological, encephalopathy apraxia, he would have problem with motor-control development,” “the child has epilepsy and problems socializing.” “I learned a lot of information. In this kind of a child you can never eradicate the problem in the child.” A little over 20 percent of the interviewed mothers sought additional information relating to their child’s diagnosis. Their strategies included reading books, asking questions, and taking their child to specialists to confirm the diagnosis. Only one mother reported using the internet to obtain information.

When asked by survey if the rehabilitation staff helped the mothers’ understanding of their child’s diagnosis, 80 percent of the respondents answered “yes, always” and 12 percent of the mothers responded “yes, most of the time.” Close to 90 of survey respondents indicated that they always felt comfortable with asking the staff questions (see Table 5.1). Women’s education level appears to have a modest effect, as mothers who completed a polytechnical program were most likely to respond always to both survey questions. University trained women were less likely to always agree that the center helps mothers understand their children’s conditions and that they feel comfortable asking the staff questions.

Five of the women interviewed could not recall their child’s diagnosis. Responses included: “the diagnosis is in my chest at home I don’t remember.” “Dr. Rodriguez explained the condition to me. I do not know the diagnosis.” “They did tell me it was in the medical region, I don’t remember exactly where it was.” “No diagnosis, doctor did not explain it to me.” These responses could be interpreted from various viewpoints. The
Table 5.1

Mothers’ Perceptions of Whether Staff are Willing to Provide Information

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<tr>
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<th>Staff helps mothers understand their child’s condition</th>
<th>Mothers are comfortable asking the staff questions</th>
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<tr>
<td>No</td>
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<tr>
<td>Most of the time</td>
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<tr>
<td>Always</td>
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<tr>
<td>No Report</td>
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<td>Total</td>
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Note. N=100

mother could not retrieve the information, the information or terminology presented at
the time of diagnosis was too complex to understand, or the medical diagnosis was not
important to the mother. As shown by Lalvani (2008) mothers often seek a social
diagnosis, in other words, mothers look for an indication of how their children’s
disability would be perceived by the community and the type of barriers their children
would face in the social world. A social diagnosis recognizes the interplay between the
state, professionals, and individuals in promoting institutional values and attitudes
towards those with disabilities (Rosenberg & Golden, 1992). By requesting this
information Lalvani posits that mothers are seeking to both expand and reject the
limitations of the medical model in explaining the meaning of their children’s disability.
Fifty-four percent of the women who participated in the study survey perceived that the
community always has a positive attitude toward disability, though only 36 percent of
respondents felt that they could always make a difference in changing the community’s attitudes toward disability. Dr. Rodriguez advocates the assignment of a social diagnosis—that is a diagnosis that considers and identifies the social difficulties and restrictions a child with physical disability may encounter—in an effort to bridge the gap between the medical model and caregivers’ understanding of their children’s physical disability, with its impact on everyday life as well as to foster positive attitudes towards those with disabilities.

**Mother’s initial response to the diagnosis**

When mothers were asked during the interviews to tell me why their children receive services at El Centro most women offered a detailed account underlining the process of identification of their children’s disability as a pivotal event in their lives. Twenty-eight members of the 34 interviewees, described their initial response to their children’s disability in emotional terms, some expressing considerable sadness, others a sense of loss, fear, and anxiety. Ana, an intensive care nurse in Matanzas’ provincial hospital said that she felt sad, “I cried so much, I cried a lot. I became pretty desperate.” Rosario’s son was born with severe asphyxia and identified as having cerebral palsy at birth. She described her feelings as “like a trauma, it was very hard, it was a hard moment. Nobody else could deal with it, you have to do everything you can.” Mayra acknowledged the loss of the child she hoped for, “It was very hard. I cannot treat him as a normal kid.”
Velma, the mother of a three-year old boy with West Syndrome\textsuperscript{xlvii}, spoke of her worries for her son, “It was very hard for me. I was not afraid of the things that were coming, but the pain that he has to assimilate himself, it is hard for me to see what he has to deal with.” One mother reported that she became emotionally sick when she found out about her child’s problem and spent time hospitalized due to the situation. The grandmother of a seven-year old boy with attention deficit disorder stated, “We were a little upset. We wanted a full child.”

A handful of mothers approached the notification of their children’s diagnosis from a cognitive perspective. Marta offered, “It is my role as a mother.” Ida stated, “I thought he would have more problems.” Elena drew upon her family’s medical background, “I was thinking it might be autism. I am relieved.” Two mothers offered a spiritual response to their children’s diagnosis. Both indicated that they prayed for their children.

The dominant response of sadness and loss reported by the majority of women supports the discourse of disability as a sad and tragic event in parents’ lives. The perspective of disability as tragic is closely aligned with the medical model that privileges science, attributes disability to biological causes and positions those with disability and their families firmly in the clinical context. Fisher and Goodley (2007) contend that this type of understanding of disability encourages families to seek experts, provides certainty and places mothers in the role of caregiver. The researchers identify this organizational disability framework as a linear model that is static and limiting in its

\textsuperscript{xlvii} West syndrome—a type of seizure disorder that can be very disabling.
recognition of the subjectivity of the child and family. Additionally, this linear approach tends to advance the caregivers’ role as good mothers, women who rely on expert opinion, accept the child’s condition and devote themselves to their child. Mothers of children with disability take the role of social actors based on projections in naming and framing disability within the particular social environment. Thus, context specific attitudes toward disability and cultural notions of motherhood inform and reinforce the adoption of the good mother model on the part of mothers with children with disabilities. The social model of disability provides an alternative framework that understands disability from a perspective that appreciates the individual with disability, values the collective experiences of the disabled, and privileges structural and contextual factors over physical impairment in conceptions of and practices toward disability (DePoy & Gilson, 2004; Humphrey, 1999).

**Mother’s response to diagnosis at the time of the interview**

The mothers in this study who care for children with disabilities are each in a different stage of their lives and have cared for their children for different lengths of time. Consequently, how mothers in this sample respond to their children’s disability at the time of the interviews can be influenced by the passing of time, life changes and their familiarity or experiences as caregivers. As discussed earlier in this chapter, Landsman (1998) posits that during the process of caring for a child with disability, mothers begin to reconstruct their narrative of their child as the personhood of the child becomes more accessible. Goodley (2007) supposes that families with children with disabilities go
through a process of *smoothing*; that is, the settling or concealing of the rough edges that distinguish the body as different and striated. The process of smoothing is where and how the disabled body becomes the living, feeling child. The assignment of *subject* to a child with disability not only allows revelation of the child’s humanity, it also may position the child within the framework of being “normal.” A few women indicated that now they see their children with disabilities as normal. Responses included:

“He progresses every day and in a group he is normal.” —Rosario

“She is no longer hypotonic, they said that she is okay.” —Maribel

“Now it is like he doesn’t have anything.” —Sonia

“She is a whole new girl now.” —Christina

“I am not worried. I see her changing. She is normal.” —Claudia

Indeed the children now viewed by their mothers as normal may have made significant improvement, even if there were initially presented with minimal disability as was the case with the children of Maribel and Claudia. The children of the other mothers have significant neurological problems. This perspective of normalcy offered by these mothers may be ascribed to the unfolding “becoming” of their child. As parents attempt to construct normalcy in family life and acknowledge their children’s humanity seen in the child’s “ongoing becoming.” Traustadottir (1991) offers that when the normal and daily activities of family life stay intact, children with disability are less likely to be stigmatized or viewed as a burden. Arguably, the naming of their child’s condition might not relate to the family’s life experience or their expectations of the trajectory of their child’s disability diagnosis. Thus the association between the child’s medical diagnosis
and notions of normal and abnormal are discounted. An alternative and empowering interpretation of the women’s responses is they are rejecting the labeling of the child and the medical model of disability (McLaughlin & Goodley, 2008).

As the children of the mothers interviewed in this study began to age and progress, most women indicated that their present feelings towards their children’s condition were “better.” The mothers attributed their better feelings toward their children’s disability to seeing their children gain skills, being “more used to it,” now “knowing what to do,” and their acceptance of or resignation to their children’s condition. Lydia stated “I am fine now. Problems in life are routine.” Although these mothers did not use the term “normal” to describe their view and emotions relating to their children’s conditions, they clearly articulated accommodating to their children’s disability in their daily lives.

About 30 percent of the interviewed mothers when asked how they felt about their child’s condition now replied, “It is still hard.” Most of the women in this group cared for the children with more severe disability and had children between the ages of three and five years. Jennifer, the mother of a five-year-old boy with severe cerebral palsy, stated, “I don’t know what is wrong with me. I have lost the hope. I am beginning to get disappointed.” I had previously met Jennifer and her son at El Centro in 2006, three years prior to her participation in this study. I was happy to see Jennifer’s son again when I returned in March 2009. The rehabilitation staff informed me that Jennifer had not brought her son to therapy since 2006 and her son had not received any services for three years. At the end of her interview, Jennifer asked me when her son would begin to walk,
a frequent question posed by parents with children with significant neurological problems. I responded to Jennifer’s question in the usual manner when asked this painful question. I listed the developmental skills her son would need to achieve before he could walk. “Well first we need Ramon\textsuperscript{xlvii} to hold his head by himself and then we need him to sit by himself, and then… and then…” It was very clear that Jennifer had very limited understanding of her child’s condition.

These women struggle with their understanding of their children’s condition and functional prognosis. They are worried and scared. Theresa states, “It is difficult. Sometimes I am up and down for days. I keep fear to myself. I sit up with him every night.” Alina is very worried that her child will not be cured completely and most likely he will not. Thelma reveals that she feels the same as she did when her child was diagnosed, “despite efforts he cannot sit still, as years go by you get afraid.” Seemingly mothers’ knowledge of their children’s diagnoses and their relation to their children’s physical and intellectual abilities plays an important role in their attitudes and expectations. Issues of access to material resources and education may also influence mothers’ understanding of both their child’s diagnosis and the severity of their condition. This group of 10 mothers from the interview cohort who reported that they were still emotionally having a difficult time represented diversity in educational level, geographical location and age. The only variable that distinguished these women from the larger interview sample was the severity of their children’s disability.

\textsuperscript{xlvii} Pseudonym
Structural and institutional arrangements clearly influence mothers’ perspectives and feelings toward their children’s conditions. Centralized professional expertise and social power, as well as limited variety and access to information resources outside of institutional structures, interface to hinder individual actions directed toward understandings of not only a specific disabling condition but also the meaning and potential impact of the diagnosis in the present and future. As Cuba’s first generation of formalized rehabilitation services continue to develop, new institutional arrangements will be required to enlist the assistance of those with disabilities and their caregivers in the creation of rehabilitation programming. Cuba’s esteemed health care system is now faced with challenges common to first world, industrialized nations—an aging population with chronic illnesses. As Cuba’s community-based primary care model of health delivery moves forward to include the management of chronic illness and disability, cultural meanings of disability within the community and cultural context will need to be explored. Structural and institutional reconfigurations of disability will guide and transform collective attitudes, interactions and understandings toward disability (Kleinman, 1988).

**How mothers make sense of their children’s disability**

Given Cuba’s unique cultural and socialist context how do mothers in Cardenas, make sense of their children’s disability? Do mothers interpret their child’s condition in a different way because they live in a socialist nation? Do women offer a spiritual explanation even though religion and religious communities are not prominent or highly
influential institutions in Cuba? Is disability interpreted through a collective perspective or is it viewed through the lens of the individual? How mothers make sense of their children’s disability is the question that grounds this study and it was the most difficult question to interpret, explain and frame. The various ways the question was posed did not translate well across cultures.

Sense making can be understood as the process individuals go through after a traumatic event that disrupts order and held meanings in their life. Sense making enables individuals to reconcile their comprehension of the event and significance of its meaning. Sense making is hypothesized to assist in restoring meaning to the event and in turn promote adjustment to the situation (Pakenham, 2008). During the first few interviews I posed the question as “how do you make sense of your child’s condition?” The term “make sense” was problematic though I did get responses that fell into the emergent themes revealed during data analysis. In the following interviews, with the guidance of the translator and member checking with the El Centro staff, the question became “how do you understand your child’s condition or how do you explain it to yourself?”

During the interviews three general, though not mutually exclusive, themes emerged: it is a medical problem, a problem during birth and I do not explain it, I accept it. A small number of mothers understood their children’s disability as a strictly medical problem. One mother prefaced her response indicating, “It was not my fault. It was the fault of medical medicine.” Another woman understood her child’s disability as a consequence of meningitis. Ivette, a young mother who lives alone with her six-year-old son with cerebral palsy understands her son’s condition as a medical problem. Ivette
stated that she knows her son has brain paralysis and that he was suffering when he was born. She shares that it took time for her to realize what her son could not do. Ivette’s son is scheduled to receive a maternal tissue transfer at Cuba’s National Center for Neurological Restoration. Ivette declared “I have faith everything will go well. It will be for the better.” She makes sense of her son’s disability through her faith in science, the cultural authority of the medical profession and the dominant medical model of disability.

Several women revisited their pregnancy to establish a record of personal responsibility as they constructed a relationship between their child’s birth event and their diagnosis of disability. These mothers made sense of their children’s disability as the result of a mistake during the delivery process. Luz related that she was never informed of the exact cause of her child’s condition. She supposed, “It may have been he had anoxia. Also he had some fetal suffering. I was in labor for 32 hours. I was there for 14 hours. I was not progressing.” Fatima and Cristina also attributed their children’s disability to delayed delivery. Marta examined her own pregnancy in an attempt to understand why her daughter has a disability.

I go over it. That I should have had a C-section. At the time there was not enough specialized treatment. I had only two ultrasounds. The baby was very big. Right now they do a lot of ultrasounds, now they are more careful. For me they were not responsible when I was pregnant. The doctor from Cardenas went to my home a few times. I had sepsis but they did not know it. In the hospital they found out and they treated me…. If he knew that she was big he could have done a C-section. He did not have the knowledge. A very big complication.

The women in each of these groups make sense of their children’s condition by locating a causal explanation that may or may not be directly related to their child’s
disability whether it be a medical problem or a mistake during delivery. Foley and Hochmann (2006) posit that as mothers of disabled children construct their personal narratives they struggle to find the cause of their children’s problem through intellectualization and rationalization. They often then project the assignment of blame to the medical profession or attribute the cause to obstetrical errors in an effort to address or dampen their own feelings of guilt or responsibility. Maternal and child health services are the hallmark and priority of Cuba’s health care system. During pregnancy each woman receives extensive surveillance, access to prenatal testing and monitoring. Pregnant women are generally admitted in maternity hospitals at least one month before anticipated delivery.

In spite of the successes of Cuba’s health care system shortage of material resources, restricted health care options and coordination within the system may indeed play a role in mothers’ perceptions of their pregnancy experiences and their relation to their children’s disability. Of course, obstetrical errors may have been the cause of a child’s disability. In Cuba a physician can be reprimanded for a medical error, though the notion of malpractice does not exist. Hence, there is often minimal benefit to a recipient of services to pursue an official assignment of negligence (personal communication, R. M., March 12, 2009).

In contrast to the causal explanation sought by some of the mothers in this study, the majority of women indicated that they make sense or understand their child’s disability by accepting it. Pakenham (2008) contends that the acceptance perspective of making sense of disability presents a view of disease or disability as part of daily life and
suggests an active integration of the condition into a general worldview, though the comments offered by the women in this study raise questions about active integration of their child with disability into everyday life or passive resignation to the presence of disability.

Juliana’s 15-month-old daughter has cerebral palsy. Juliana worked as a teacher and now stays at home to care for her child. She reports that when her child was born her birth was delayed and she did not receive oxygen to her brain for 30 minutes. When asked how she understands her child’s disability she replied, “I don’t find explanations. I just have to deal with it and fight for her.” Elsa first revisited her pregnancy indicating that she told herself that she “did everything the doctor said” and then replied “I don’t explain the child. I try to make progress for the child.”

Two mothers responded, “I never asked myself why.” Angelina continued, “I just deal with it, I accept it.” Rosario added, “He is here and I have to deal with it. There is not an exact reason or chosen person for that.” Carmen, the mother of a child with West Syndrome, did ask the question why, “I asked myself ‘why me when there are other people who do nothing for their child.’ But it was my moment…. I went to a psychologist. The answer I found for myself is that my son is dependent on me. It is being a mother. I love my son.”

Physicians played a role in some of the mothers’ sense-making of their children’s condition utilizing downward comparison to encourage mothers’ acceptance of their situation.
The doctors were very tough, they talked to me in a tough way, it is what you have to do in this situation. They said your child is not the only one. There are many other mothers in the same situation. They talked until I understood, and then I got it. I love my daughter and I love her the way I do. (Juanita)

I felt very bad when I found out. I had to go to the child psychologist. Now that I know he has grown, I understand that he can integrate into society. That he can understand others. The doctor kept telling me that he is not that bad. I thought that he was trying to make me feel better. But now that I see him, I see that he can actually get better. (Fatima)

I went to a doctor in Havana. He said that the child is not great, but better than other kids. At least she can walk. You cannot be blind. You have to deal with what you have. I know this is a life time situation. (Belkis)

Without overlooking aspects of individual agency and efforts to assimilate their children into the social fabric embedded in the above comments, these responses of acceptance can be explained mostly by the sociocultural environment and the social location of the good mother in Cuban society. Historically and particularly during Cuba’s Special Period, Cuban citizens have been asked to accept conditions of hardship and sacrifice. The acceptance of a child’s disability is both an indicator of individual emotional development and normative cultural behavior. The state’s collective ideology serves to transmit and reinforce attitudinal and behavioral expectations toward disability and the role of women caring for children with disabilities—that is, the role of the devoted, accepting good mother. Institutional social approval is conferred on the good mother who cares for her child with disability. A number of mothers in this study indicated that it was their physician, at the time of their children’s birth or during follow-up clinic visits who guided their understanding of a new role as a mother of a disabled child. As noted in a previous chapter, the Cuban doctor operates as a symbolic
representation of the Cuba’s revolutionary ideology, cultural authority and extended family member (Perez, 2008; Warman, 2001). The family doctor visits patients in their homes, provides counseling as well as medical intervention and is available to all community members any time of the day or night. As in the example of Juanita’s experience in many of the instances the women’s physicians through their cultural authority stood in as proxies for the state in communicating mothers’ social role and expected practices. That is not to say that acceptance of disability is not a good objective. It certainly is, though the question to be asked is if this form of acceptance is an action of agency or a passive response to cultural expectations. The women in this study did express and enact individual agency. One example of agency is shown in their seeking and giving advice.

Advice

The role of advisor to young mothers who had recently been informed of their children’s disability was cherished by many of the women who participated in the interviews. Women generously shared information acquired through socios and informal networks with each other, pooled resources to arrange transportation to and from the clinic, offered their own medical opinions as to the course of treatment required by children other than their own and comforted each other. Some mothers spent the better part of the day at El Centro socializing, educating and supporting other women. The advice mothers gave to each other was to fight for your child, to love your child and to be a good mother.
The large majority of women framed their advice within the model of the good mother. Themes within this response included accepting the condition of the child, following the doctor’s advice and devoting to your child. Angelina clearly has pride in her role as an advisor,

Other mothers ask about her (daughter’s) situation. Mothers like to be informed…. I tell them to come here. To ask for help…. My motto is if you are a mother you need to deal with whatever life gives you. I cheer up the professional mothers. I always give advice to help mothers. I am a very mature person. My mother made me who I am.

Carmen was succinct in her advice to other women, “they did not ask to be born. Whatever happens you have to be there.” Mayra took on a broader view,

I think that many mothers, I am not saying that I am the best, rarely see the problem of their child, they are not well oriented, they do not come here to understand. I think they should be worried to understand. They (child) need a lot of time, sometimes the time you dedicate to your children it is not the same. My advice is to be more worried about the child.

Other responses included: “to live for that child,” “resignation, devotion and dedication,” “you must accept the condition of the child and face it,” and “I would advise mothers not to stop, don’t give up.”

Five of the mothers interviewed advised other mothers to be patient, provide the child with love and not overprotect them. The third theme that emerged when interviewees offered advice was luchar, to fight. Although only five respondents fell into this category, the terms luchar and estar en la lucha, to be in the struggle (Marrero, 2003), were commonly used by many respondents throughout the interview process. My
preliminary impression of the use of luchar was associated with the numerous billboards throughout Cuba that reinforced revolutionary language directed toward US policies and the economic crisis. Thus, I initially interpreted these responses almost as a revolutionary and cultural slogan or indication of advocacy or perhaps activism. I came to discover upon member checking with staff and probing during the interviews that the intent of luchar in the context of the study was to persevere, to continue in the struggle to acquire resources or opportunities for your child.

Some of the experiences shared by the women interviewed in this study are similar to those of women who have children with disabilities in other sociocultural contexts. The mothers’ struggles to understand conceptions of normal versus abnormal, make sense of what happens, examine personal responsibility and hold onto hope that their children can be viewed as universal themes. Understanding of the child’s diagnosis can also be seen as a cross-cultural phenomenon, as the diagnosis does not convey what the child can do in a particular context. Thus, there is always a disconnect between the labeling of the child’s diagnosis and mothers’ experiences of their children in daily life. I suspect that in many contexts it is the mother who first notices her child’s condition. Notification of an infant’s disability at birth or labeling of disability after the child’s first year is common in scientifically advanced and industrialized nations. Though Cuba is not an industrialized society, the nation’s health care system is recognized for scientific achievements and models of care. Emotions of loss and sadness, tensions of uncertainty, as well as trying to make sense of a diagnosis can be understood as a universal response to an unexpected outcome and a pivotal event in the lives of women whose children are
identified with a disabling condition. What distinguishes the Cuban mothers in this study is the dominant medicalized perspective and understandings of disability, limited sources of information to gain better understanding of their children’s conditions and gaps in coordination of health system services, medical resources and support services. The following chapter provides a broader examination of the impact of material conditions and institutional arrangements on the daily lived experiences of mothers caring for their children with disabilities in Cardenas.
CHAPTER 6
MOTHERHOOD AND MOTHERING A CHILD WITH DISABILITY

Interviewer: “What do you enjoy about being a mother?”

“I enjoy most the love that they give me.” —Elsa

Elsa is a 24-year old single mother of two children, a two-and-a-half-year-old boy and a
girl who is 18-months-old. Elsa’s son receives medical and dental care, physical therapy and
occupational therapy at El Centro. He is scheduled for appointments three times a week. Elsa
lives in a small town with her children and her grandparents. The town is 45 minutes from El
Centro. Elsa takes a taxi or pays for a private car to bring her to El Centro. It is difficult for Elsa
to bring her son to therapy every week “because transportation, it is very hard.” She comments
that at times mothers discontinue services at El Centro due to transportation problems. She hopes
to own a car so that she can “help her son better.”

Elsa studies psychology at the University of Colon. On the days that she has
classes, Elsa wakes up with her children, makes breakfast, does the laundry, dresses the
kids, performs prescribed exercises with her son and tries to spend time with each child,
stating, “I don’t want to seem to give more love to one of them.” Elsa attends school in
the afternoons often going to bed between 8:00 and 9:00 in the evening as she is “so
tired.” She feels that her experiences as a mother do not have to be different than those of
mothers who do not have children with special needs—it only requires the “need to be a
little more careful.” Elsa’s grandparents help with the care of her children. When asked if El Centro provides services that support mothers’ caring for their children Elsa responded “most of the time,” and suggested that El Centro could offer additional transportation services, counseling for mothers and classes for parents.

This chapter illustrates how a group of women whose children receive rehabilitation services at El Centro view their experiences as mothers and caregivers. The women’s daily routines, the joys and challenges they encounter during mothering, the support they receive and the burdens they experience are explored within each individual’s particular socio-cultural context. This analysis brings together data collected through the survey questionnaire and the narratives of the mothers who participated in the study interviews. The variations in family arrangements, how families work out roles and routines, and implicit expectations of maternal self-sacrifice are knitted together in the perspectives of the women mothering their children with disability.

Families, Households and Relationships

Households in Cuba typically take on various forms and arrangements, though gendered roles continue to exist in caring for the home and family. Legal marriages remain as the ideal foundational family structure in Cuba despite increased rates of consensual unions across racial groups and levels of economic access (Safa, 2005; Pertierra, 2008). Approximately two-thirds of the women who participated in the survey component of this study identified themselves as married; two percent reported their
marital status as a consensual union. Seventeen out of the 100 women surveyed indicated that they were divorced. Safa (2005) in her comparative examination of family structures and patterns in Cuba, Puerto Rico and the Dominican Republic found that the boundary between legal marriage and consensual union was not very clear in Cuba, thus the sample report of close to two-thirds of the women being married may be inflated. Safa attributed this blurring of marital boundaries to policies of the Revolution. Revolutionary initiatives including income and class equality, extension of legal rights to women in consensual unions, legitimacy of all children born out of wedlock and the weakened status of religious organizations supported the expansion of consensual unions as legal marriages lost legitimacy.

Multi-generational families as well as female heads of household are part of Cuba’s diverse family landscape. At the same time it is not uncommon for immediate family members to reside in different households (Pertierra, 2008). As indicated by Velma “I live with my mother, brother, niece, son and husband.” Most of the mothers interviewed for this study reported living with their spouse/partner and child often with the addition of a grandparent, sibling or nephew or niece. Alina lives with her child, her husband and one of her brothers. Mercedes reported, “My household includes me, [the grandmother who raised the child], the child’s mother, father and stepmother.” Some reported households are smaller and suggestive of a typical nuclear family. Maria and her husband live in the countryside with their son. Ana who was orphaned at the age of

xlivi Five women in the sample indicated other to the question of marital status, three respondents did not answer this question.
fifteen years proudly proclaimed, “I am married 20 years and I live with my husband and baby.” As in the case of Yvelis some households can be rather large and extended: “We are a big family. It is me, my husband, my two children, my aunt, lots of people live with us.”

An interesting aspect of the reported household structures is the inclusion of the woman’s consanguineal family members in the home with no respondents reporting that they live with the husband/spouse’s family. Due to short supply of housing units in Cuba, relatively few individuals live alone. Within the interview sample only one interviewee reported living alone with her young son, though she does live close to her immediate family. “I live with the boy by myself; I live near my mother, brother and sister-in-law. Father of the boy helps me but he doesn’t live with me” (Ivette).

These distinct family arrangements may be explained in practical as well as cultural terms. Cultural notions of family, women’s roles in the household, and a shared collective vision serve to extend the concept of family beyond traditional western notions of a “nuclear unit.” Cuba’s colonial Caribbean history in concert with national legislative initiatives enacted through the 1975 Family Code, along with persistent post-revolutionary economic constraints have contributed to perceptions of the Cuban family as a matrifocal institution that privileges “consanguineal relationships over conjugal bonds” (Safa, 2009, p. 43). In spite of the state’s preference for familial stability associated with legal traditional marriages, consensual marriages are very common, resulting in the post-revolutionary state’s recognition of the mother and child as the core of the family unit (Safa, 2005). Motherhood in Cuba is sacrosanct and protected.
Material conditions, especially lack of suitable housing, similarly influence the methods of housing distribution and the composition of household structure. Housing shortages clearly impact family living arrangements as multigenerational and extended families often live together in crowded spaces. Conversely, scarcity and limitations in housing, in addition to family situations or conflicts, results in the splitting up of immediate family members who then do not all reside in the same households. As stated by Miriam, “We all don’t live together, but we are close. He is separated from his mother. They love each other, but they have their conflicts.” Maribel has a teenage son from a previous marriage. In an effort to integrate her family she lives on the second floor of her building with her current husband and baby while her 19-year-old son lives on the third floor of the same building with her parents. Nancy’s split household is solely a function of physical space as she states, “The child [who receives services at El Centro] lives with me, (grandmother) and her grandfather. My daughters live with their boyfriends in a different house. My house is too small for everyone.”

The distinctions between households and families in Cuba, like those between legal marriages and consensual unions are not very clear. Ann Cristina Perttierra (2008, p. 713) sheds some light on the particularities of these constructs as she states “where one resides and to whom one belongs are often quite distinct in Cuba” as families extend outside the physical household space due to housing shortages and small houses or apartments. Reference to family usually includes closest relatives while belonging to a household suggests living in the house of one’s mother or grandmother.
Acquiring or relocating to a new residence is a difficult process in Cuba. Although over the past few years buildings in Old Havana have been repaired and refurbished in order to boost the tourist economy, about half of the residences in Havana proper are rated as substandard or beyond repair. Families in need of housing are reported to face a 10 year waiting time (Krull & Kobayashi, 2009). The customary practice of moving to a new residence is to barter homes with other Cubans or to pursue opportunities through the informal economy. One woman with a child with severe disability who lives quite a far distance from Cardenas pursued relocating to the town so that her family would be closer to the rehabilitation center. She submitted an official request of assistance to a few non-governmental organizations without success.

Interviewees also noted the extension of family beyond Cuban borders, as some women acknowledged members living abroad in their description of their immediate family.

I live with my husband and two daughters. But I have had family problems. My mother, fathers and sisters have moved to the United States. I am their only child in Cuba. I am very lucky to have my husband. He is very supportive. (Angelina)

My mother passed away years ago. My father is in the US. I live with my sister, my nephew, my husband and the boy. (Fatima)

Krull and Kobayashi (2009) observed in their study of Cuban women’s sociopolitical views across generations, that it is common for families to maintain strong ties with relatives in the United States, especially the current generation of emigrés who left the island primarily for economic opportunities.
This study resonates with key findings in the literature that Cuban families are multi- or tri-generational, often with more than one woman performing household activities and caring for children. Although men may be present in many families, a distinct matrifocal structure exists in most families as ties between the woman, her children and female kin are valued over conjugal connections (Safa, 2005). As noted by Alicia Roca (2005) during her time spent with women in Cuba’s Manzanillo province, many women viewed their immediate family as their priority. One woman from Manzanillo reflected that although she loved her husband she was thinking of leaving him so that she could move back to her hometown to be with her sisters. Institutional practices of housing distribution impact on living situations as family members are split into different households, and in other circumstances homes are crowded with additional relatives (Pertierra, 2008). Despite advances in gender equality, women continue to be associated with the domestic sphere and attendant expectations of household management and childcare. Cuba’s economic crisis has also contributed to household configurations with the adoption of extended family members into the house in order to pool survival strategies and economic resources (Safa, 2009).

Not one of the interviewees identified or made reference to their child with disability when asked to describe the family arrangements within their household. Given the parallels between findings of this study and the academic discourse surrounding family and household structure in Cuba, the respondents presented descriptions of typical Cuban living arrangements. The question then becomes how does the presence of disability within a household influence familial relations and daily activities? In other
words, does having a child with a disability solicit a more cohesive family unit, enlist additional support from the mother’s kin or does it have no influence on household arrangements? When the mothers were asked to talk about their families, indications of disability within the family began to emerge, expressed in themes of family cohesion:

“My family is very united. We support each other. We are very together.” —Marisol

“We are a normal family, we have good communication. After the child we are more united.” —Carmen

“Our family is quiet, united.” —Angelina

“We are okay. We communicate, cooperate. We have assimilated very well to the child.” —Velma

Difficulties with family members:

“I have a problem with a relative. Relation between mother and son is not very good.” —Miriam

“I have a problem with my uncle. I tried to do the exercises with the child… because my uncle did not want me to be in the house. We want to build a house so the child can have a more healthy environment.” —Marta

“My husband is not supportive. He takes me away from my son.” —Thelma

And family support:

“My mother sometimes helps on weekends.” —Jennifer

“My husband works with the girl as hard as me.” —Sara
“The father helps with the child. I get help from my mother, brother and sister in law.” —Minerva

“The family tries to understand and to help him as much as they can.” —Rosario

The above quotes begin to reveal the experiences of these women who mother a child with disability. Although most of the mothers did not openly state at the beginning of the interview that “the child,” “the girl” or “him” was disabled, nestled in each statement was the presence of an individual that required a certain type of attention. Information obtained from the study questionnaire provides a backdrop to understandings of family arrangements and social support within the study’s particular context. The full sample of 100, including women who were interviewed and mothers who were not interviewed, was asked to indicate who in the household mainly cared for the child with disability, who was most responsible for household activities and which family members assisted in the care of the disabled child. Sixty of the 100 women surveyed identified themselves as the primary caregiver of their children with disability (see Table 6.1). Sixty-five percent of the women are primarily responsible for the household (Table 6.2). Over one-third of the respondents indicated the need for help in their home even though a robust 91 percent of mothers reported that a family member helped them in the care of the child with disability (Table 6.3). Close to 60 percent of the respondents identified the collective family as helping most with the care of their children with disabilities. Twenty-five percent of mothers reported their spouse/partner as the family member who provided the greatest assistance with their child (Table 6.4).
Table 6.1

*Distribution of person primarily responsible for child with disability*

<table>
<thead>
<tr>
<th></th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>60%</td>
</tr>
<tr>
<td>Other</td>
<td>19%</td>
</tr>
<tr>
<td>Mother and spouse/partner</td>
<td>14%</td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>3%</td>
</tr>
<tr>
<td>No Report</td>
<td>4%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
</tr>
</tbody>
</table>

*Note.* N=100

Table 6.2

*Distribution of person primarily responsible for the home*

<table>
<thead>
<tr>
<th></th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>65%</td>
</tr>
<tr>
<td>Other</td>
<td>17%</td>
</tr>
<tr>
<td>Mother and spouse/partner</td>
<td>12%</td>
</tr>
<tr>
<td>No Report</td>
<td>4%</td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>2%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
</tr>
</tbody>
</table>

*Note.* N=100
Table 6.3  
*Distribution of Family Members Help with Care of the Child with Disability*\(^{xlxi}\)

<table>
<thead>
<tr>
<th></th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>91%</td>
</tr>
<tr>
<td>No</td>
<td>7%</td>
</tr>
<tr>
<td>No Report</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

*Note.* N=100

Table 6.4  
*Distribution of the Family Member Who Helps Most with Care of the Child with Disability*

<table>
<thead>
<tr>
<th></th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collective family</td>
<td>58%</td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>25%</td>
</tr>
<tr>
<td>Grandmother</td>
<td>9%</td>
</tr>
<tr>
<td>Friend</td>
<td>3%</td>
</tr>
<tr>
<td>No Report</td>
<td>5%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

*Note.* N=100

\(^{xlxi}\) Although 7 percent of respondents in Table 6.3 indicated that no family members help in the care of their child with disability, Table 6.4 does not indicate that any respondents reported no family members helped most with the care of the child—though the no report response may capture a portion of the 7 percent in Table 6.3
When asked by survey if El Centro offers the services needed for the child with disability close to 60 percent of respondents replied yes, always. Sixty-two of the one hundred mothers who completed the survey reported that El Centro always offered support for mothers. (See Table 6.5).

Table 6.5

*Distribution of Responses to El Centro Service Delivery*

<table>
<thead>
<tr>
<th></th>
<th>Center offers services needed for child</th>
<th>Center offers support services for mothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Most of the time</td>
<td>34%</td>
<td>31%</td>
</tr>
<tr>
<td>Always</td>
<td>59%</td>
<td>62%</td>
</tr>
<tr>
<td>No report</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

*Note. N=100*

Young mothers within the age group of 18–24 years and those with children between the ages of newborn to one year were more likely to respond “always” to each statement. Mothers’ affirmation that El Centro always provides the services needed by their child with disability decreases as the age of the mother advances. In turn, as the age of the child increases mothers are less likely to indicate that the needed services by their child and maternal support are always available. These findings may be explained by the inexperienced expectations of young mothers and the evolving presentation of their child’s condition as they may anticipate that their children will fully recover with therapy. Additionally as mothers and children age during the rehabilitation process they may
require a greater range of physical and support services not presently available at El Centro or in families’ homes.

Maternal education level and the child’s condition also play a role in how mothers responded to the availability of services for their child and support for themselves. Women whose children were identified with congenital conditions were more likely to report that El Centro always provided support and services, though the group of children with congenital conditions was a very small portion of the sample accounting for only five percent of the total. Women who care for children with neurological diagnoses comprise thirty percent of the sample and are the least likely to agree that El Centro always provides support services for mothers. Mothers who attained a degree at the polytechnical level are the most likely to always agree that El Centro provides the needed services for children and support for mothers. University trained mothers are the least likely to respond always to the provision of services and support. Additionally women who were not interviewed during the research process were more likely to agree that services and support are always available (Refer to Table 6.6). This finding can be attributed to the interview group’s larger representation of older children and children with neurological conditions. Examination of the women who participated in both the study survey and interview allows a more nuanced view of the everyday experiences and needs of mothers caring for their children with disabilities.
The Everyday Experiences of Mothering a Child with Disability: Routines, Joys and Challenges

Thirty-four of the one hundred women surveyed in this study participated in semi-structured interviews. The interview sample presents a diversity of educational level, age, marital status, and geographical location. Less than half of the mothers interviewed are educated at the university level, close to seventy percent of the women report being married, and ten of the thirty-four women work outside of the home. The children of the mothers interviewed range from seven months of age to eleven years and present with a variety of disabling conditions, though most of the children are identified as having a neurological problem. Compared to the general sample the interview group is more likely to have a child with a neurological condition, more likely to have a child between the ages six and eleven years, more likely to have a university degree and less likely to work outside of the home. Additionally, in comparison to the non-interviewed sample the mothers who were interviewed are more likely to reside in Limonar, a poor section of the Matanzas countryside; and in the province capital, the city of Matanzas. This finding can be explained by the fact that young children born in Cardenas with developmental problems are routinely referred to El Centro from local family physicians for early intervention or preventative services. Children with more pronounced delay or disability who live outside of Cardenas often travel to El Centro for rehabilitation as their local community is unable to provide the services required by their conditions. The following table (6.6) provides an overview of the demographics of the interview sample, the non-interviewed and full sample.
It is of note that demographic variables relating to race and socioeconomic status are not included in the survey and thus not reflected in the following table. Cuba neither publishes income distribution statistics (Mesa-Lago, 2007) nor collects or categorizes racial data. Thus, these categories are not reflected in the analysis of survey data. However, the interview process allowed for further exploration of racial identity and economic position within the interview sample. Three of the 34 women interviewed presented as Afro-Cubans. Each of these women were university trained, one woman was working as a high school math teacher, another as an intensive care nurse and the third mother was completing her degree in psychology. When questioned about the low representation of black Cubans in the interview sample, several informants suggested that Afro-Cuban mothers tended to be more self-sufficient and stronger, therefore not requiring the support of El Centro. Variations in income status emerged during the interviews as women reported financial support in the form of remittances and material goods from families abroad and access to the tourism sector.

Table 6.6

Comparisons of interviewed/non-interviewed demographic data

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Table 6.6

*(continued)*

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175
Mothers’ reports of their everyday experiences when caring for their child were varied and distinct. The following three vignettes give an account of the joys, challenges and everyday routines expressed in relation to caring for a disabled child.

Maria is 26-years-old and lives with her husband, infant, six-year-old son and her mother in Matanzas, the province capital about 20 miles from El Centro. Her “day as a
mom” begins with making breakfast and then taking her six-year-old son to school. Maria then hitchhikes to El Centro with her baby son spending several hours in the clinic stating, “Yes, I am here all day.” When she returns home she cleans, does the wash and cooks for the family. In the evening Maria helps her son with his homework. Maria also works in a part-time job as a cement technician. She has attended school remarking, “I have no time to myself, I even had to stop studying and drop school.” Maria reports that she and her husband share household and childcare responsibilities, though she remarks “my husband helps me out, but he is a driver, he is never home.” Maria’s mother and sister help her with her baby son as well. Support services that Maria feels would be most helpful to her and her family are transportation, classes for parents and more therapy for her child. Maria feels that her experiences of motherhood are different than those of women who have a “normal” child indicating the lack of time to attend to her personal care.

Velma wrote at the end of her study questionnaire “Quiero agradecen a todo el personal por el amor y la dedicacion con que hacen su trabajo. Gracias.” Velma is the 24-year-old mother of a three-year-old son with a progressive neurological disease. She is the primary caregiver for her child and household. She lives in Matanzas with her mother, brother, niece, son and husband. She enjoys seeing her son grow and identifies her biggest challenge as a mother is to make it so “that he can go to school. He does not have so much ability. He can not feed himself with his hands, a spoon or a fork.” Velma

1 Translation—I want to give thanks to all the personnel for the love and the dedication that they have in their work.
attends the university studying economics on Saturdays. She and her son come to the clinic once a week. Up until six-months ago he was attending therapy three days a week. Velma states that she “gets to the clinic by myself. No one helps me. I had transportation, but they took it from me.” During a typical week Velma takes her son to a kindergarten close to her house one day a week and makes lunch. Her son then takes a nap and in the afternoon they go to the park. He watches television at night. Velma studies while he sleeps. Velma receives assistance caring for her son from her entire family—her husband, mother, brother, and friend. Velma feels that her experiences as a mother are “sometimes a little bit different, sometimes a bit sad, but I learned to enjoy him.”

“I got a degree in economics for a career in tourism. I put a lot of time into it. But when the child was born with difficulties I had to quit. It is not about the money, spiritually you feel different when you work.” Mayra is 39 years-old and the mother of a 10-year-old boy with attention and behavioral problems who receives rehabilitation services, as well as another five-year-old son. She is married, attended university and receives some support for the care of her elder son from her husband and brother. Mayra is also caring for her parents who are sick. She enjoys going to cultural activities though “right now “ she doesn’t have the time to engage in them. “Every day with the child is challenging…. I have to give time to the child. The other one also needs time. My husband needs things, my parents things. I try every day to be with each person. I enjoy much to see how my son develops and the results he gets…. I think it is because of my dedication.”
These three vignettes reflect themes common to the narratives of the group of women interviewed in this study. Some of the themes are particular to women mothering a child with disability, others may be more common to the experience of motherhood in general and several are specific to Cuba’s cultural context. The second shift that women take on in their roles as mothers and daughters in the care for their children and parents is evident in Cuba and other social locations. The tensions between career and motherhood are matters that are acknowledged and evaluated by many women across various cultural, social and geographical contexts. Invisible unpaid work, caregiver burden, social isolation, denial of personhood and transfer of professional responsibilities are germane to the experiences of mothers caring for their children with disability. Cuba’s material conditions and institutional structures that shape the form and access to disability and support services can be seen as exclusive to the cultural context in which this study is situated. The findings gleaned from the interview questions surrounding motherhood and mothering are organized into three broad topics that came forward during analysis of the data. These topics are: perspectives and experiences of motherhood; caring for a disabled child and access and utilization of social support.

**Perspectives and experiences of motherhood.** The large majority of women who participated in this study enjoy being a mother. Many state that they take pleasure in *everything* about being a mother. Others identify the closeness of breastfeeding, seeing their child grow or progress, or hearing their child laugh as joyful maternal experiences. A handful of women refer specifically to the love they receive from their child as what they cherish most about motherhood.
“I like when she says she loves me.” —Belkis

“I enjoy most the love they give me.” —Elsa

“I enjoy my son. When he wakes up and he kisses me.” —Fatima

“I love my daughters. They keep me strong.” —Angelina

Elena, a mother of three sons, expresses a sentiment relating to motherhood also offered by other women in the group: “The best experience a woman could have is being a mother.” As previously presented, motherhood in Cuba is valorized, as the role of women as mothers is reinforced by the patriarchal cultural context and institutional arrangements. However, the view of motherhood that most members of the research group present may be representative of a more general notion of the emotions of mothering, but not necessarily the practice of mothering, and in particular caring for a child with disability. The responses that the women gave in relation to what they enjoy most about being a mother made no overt reference to their children’s disability, suggesting their identification with generally held ideas of motherhood.

Sharon Hays (1996) in her study of intensive mothering examines American women’s attitudes and values toward female parenting. Hays suggests that for a number of women children may provide a unique type of love that is unconditional and accessible. The birth of a child can also offer the mother someone to nurture and love completely. This analysis can be applied to the responses offered by the mothers of this study. Hays’ perspective draws attention to the strong desire of some women to give and receive love from a child. Cuba’s social construction of the family core as the mother and child unit encourages the strong relationship between mother and child. During the
interviews that I conducted the term “good mother” was informally offered as an
exemplar of motherhood. Hays describes the good mother as a woman who views child
rearing as more important than the pursuit of personal goals and the willingness to deny
her own interests, at least as constructed by American society.

Ideologies of the good mother exist inside and outside of Cuba and thus can
perhaps be conceived as a universal ideal of the loving, caring mother that is then enacted
according to cultural context or scripts. The good mother is one of the varieties of cultural
scripts that Cuba permits within its social structure. In her paper on Cuba’s sexual
tourism Theresa Marrero (2003) describes cultural scripts as a set of implicit behavioral
codes that are “deciphered, understood, negotiated and enacted” (p. 238). As actors in
this script the Cuban good mothers adhere to predictable patterns and behaviors in
particular contexts and circumstances. The good mother script in Cuba has the potential
to provide women not only with a sense of self fulfillment, but also afford material gain
in the form of access to services, enhanced attention of a health professional and
acquisition of resources. An example of the usefulness of the good mother role is evident
in how women responded to Cuba’s economic crisis. When confronted with scarce
supplies of food and household necessities, Cuban women put their professions aside for
lower status jobs and augmented their second shift responsibilities as they took on the
burden of standing on long lines to get food for their families and maintaining the health
and wellness of their children, parents and extended family members.

Yet the description of the good mother offered by Hays can also be associated
with Cuba’s collective, socialist ideology. Angelina lives in the countryside and has two
daughters that she adores. She reports that her first priority is her kids and then her house. Angelina was trained as medical assistant and gave up her position in order to care for her children and work together with her husband. In general all Cubans, not only women, prioritize the needs of the group over the aspirations of the individual as evidenced during Cuba’s economic crisis. Although as noted in a previous chapter, Cuban women had most of the sacrificing during the Special Period. Accordingly the role of the good mother perhaps has a more collective identity in Cuba than in other cultural contexts. Nonetheless, individual adoption of the “good mother” role can furnish women with cultural capital in negotiating the informal economy and access to various sectors.

In contrast to the interviewees’ responses to what they enjoy about motherhood, when asked about their challenges in mothering all participants identified their child with disability as their greatest challenge. The responses ranged from generalities such as:

“The biggest challenge is to have a child like my son.” —Thelma

“Everyday is a challenge—it is hard to orient.” —Mayra

“Challenge is having a child with a diagnosis.” —Carmen

To specific concerns regarding the child’s skill development:

“Challenge is to get the child to walk perfectly.” —Sonia

“It is for me to help him at school.” —Margarita

“Biggest challenge is crossing the street with him.” —Mercedes

And inferences to mothers’ concerns about parenting their children effectively:

“The challenge is to raise the child properly… to provide confidence.” —Theresa

“Challenge is when I get sick.” —Rosario
“To guide them on the right road.” —Elsa

“Challenge is to adapt myself. I get sick from the stress.” —Marta

Contrary to the remarks offered by mothers regarding the joyful aspects of mothering, these comments suggest the prominent location of the child with disability within women’s experience of motherhood. All mothers who identified their children as their challenge provided an emotional response that suggested a sense of burden, difficulty understanding their child’s condition or needs, or feelings of helplessness. Women who listed their concerns as skill based goals for their children seemed to take on a pragmatic approach to an issue or problem that has the possibility of resolution. The last grouping of responses underscored women’s uneasiness with their own skill set or attributes as a mother caring for a child with disability. Research has shown that parents of children with disabilities often present contradictory emotions as they navigate the tensions of hope and no hope, joy and sorrow (Kearney & Griffin, 2001; Larson, 1998).

Variations in responses, offered by the women surrounding the challenges they experienced in the care of their children with disabilities, could be influenced by their educational level, the age of their children or the extent of their children’s disability. Contrary to expectations, however, these factors did not have an influence on how mothers identified challenges. Previous studies have shown that the ecological context contributes to how women perceive the challenges they face when mothering a child with disability. McGuire et al. (2004) found that environmental variables have more of an impact on mothers’ daily experiences than personal factors. The researchers contend that gaps in social support needed by families of children with disability can be attributed to a
lack of understanding of the experience of disability at individual and institutional levels, thus leading us to the importance of mothers’ daily experiences when caring for their children with special needs in informing social policy and contributing to the development of relevant and supportive disability services for children and their families.

**Caring for a child with disability**

Even though the majority of women in this study reported their challenges in mothering in relation to their child with disability, less than half of the participants viewed their experiences of motherhood as different than those of mothers caring for children who are typically developing. The interviewed group participant responses split into three categories. Motherhood experiences were perceived as *the same* as mothers who care for typically developing children, *about the same* or as *different*. Time was the most salient variable in distinguishing the experience of motherhood as same or different. Mothers from the group who viewed their experience of motherhood to be *about the same* as other mothers uniformly responded that *maybe* the only difference is that more time is needed to care for a disabled child. Within the interview group the interviewees who responded *about the same or different* than those experienced by women whose children are “normal” are essentially offering a similar response. Mayra views her motherhood experiences as different than the norm stating, “It is not the same. I need to teach him, wait for a response.” Mercedes devotes all her time to her son, and sleeps with him every night due to her fear that he will stop breathing. Maria sees the demands
time in caring for her child as taking away from her personal needs and self-identity stating “I don’t have time to keep up with my hair and nails.”

Diane Hammon Kellegrew (2000) posits that with the exception of childcare activities, mothers of children with disabilities accommodate daily routines surrounding household tasks in a way that is comparable to families from a similar cultural background with children who are typically developing. The findings in this study confirm Kellegrew’s observation. All women in Cuba, including the participants in this study, tailor their household tasks to accommodate the considerable amount of time needed to acquire household supplies, access transportation and negotiate the informal economy. As suggested in the literature, mothers of children with disabilities experience an additional burden in the care of their child as physical management, supervision and everyday activities require a greater allotment of time (Green, 2007). As such the daily routines and activities of women mothering a disabled child have the potential to become overwhelmingly child intensive.

In addition to issues of time mothers when describing their daily routines imply their sense of loss of personhood and subordination of their self-interests. Mayra enjoys attending cultural events, though because she must care for her son and parents she is unable to participate in these activities. Some women, such as Maria, reported the need to stop work or school to take care of their child. However, most of the women in a variety of ways expressed their displacement of self in relation to the other, most notably their child with disability.
Minerva states, “The only thing I have done this year is take care of the baby, I have done nothing for myself.” Marta expresses a similar sentiment, “On a typical day I am in the house with my daughter. I don’t do anything for myself.”

Thelma, a 34-year-old woman with two children described her day as follows: “I devote most of my time to my son. I exercise him in the morning and afternoon. I live in the countryside; I take care of the animals. Sometimes I like to read. I don’t have enough time to do anything for myself.” Ida’s remark “I have to do it all by myself,” adds a dimension of social isolation to her daily mothering of her child with disability.

Other women in the group offer a perspective of their daily activities in a different manner, calling attention to the perhaps mundane aspects of caring for their child.

“I make breakfast, prepare meals, bath at 11:00 pm.” —Nancy

“Nothing is different, everyday is the same routine.” —Alina

“I don’t do anything new except take care of the child.” —Carmen

A few women do talk about activities that indicate their self-interests and a balance of experiences with their children. Juanita is a 26-year-old mother of a child with Down Syndrome. She also cares for her elderly parents who live in Cardenas. Juanita spends her days caring for her child and bringing her to the clinic. When she wakes up in the morning she sometimes takes a bike ride and each afternoon finds new activities to engage in with her daughter. Sara, who also has a daughter with Down Syndrome, tries to achieve balance in her life and activities: “Of course we are also providing constant attention to her. We are always like a teacher to her or else she will not progress. I like going out, I try to make time for everything. We take her every where, parties, the
Rosario begins the description of her daily routines with the statement “my life is my child.” She then continues to list the activities that interest her and she participates in, such as sewing, telling stories, going out in the neighborhood and to the beach.

It is not clear which factors or situations distinguish the mothers who are weighed down by their caregiving tasks and the women who can integrate activities of their own interests into their daily regime. It is my impression that the severity of the child’s disability as well as available social support has an important effect on the women’s ability to engage in personal and meaningful activities outside the realm of caregiving. However the cultural context that is favorable to women in the role of the devoted, good mother cannot be overlooked. As Glenn (1994) notes the good mother encounters the risk of subordinating her own agency in devotion to her child as the lines between self and child become blurred. In patriarchal societies, such as Cuba, women are typically assigned the caregiver role based on gendered differences of nurturing and intuition (Hays, 1996). That role is particularly problematic when caring for a child with disability, as it is based on an assumption that maternal intuition, devotion and nurturing are sufficient to provide the care to a child whose care often requires a specific knowledge base and skill set. Consequently cultural arrangements of childcare that rely on the support of the collective family appear to be limited in meeting the needs of women who mother children with disability.

When asked by survey what resources were needed to assist mothers in the care of their disabled children the interview group was distinguished from the non-interview group. The interviewed group was more likely to suggest the need for transportation
services, equipment for their disabled children, classes for parents, additional therapy for their children, education for siblings and education at the community level about disability. Close to seventy percent of the interview respondents identified transportation as a much-needed resource. During the interviews many women relayed their frustrations and the excessive time demands they spent on accessing transportation to El Centro. They also discussed the amount of time they spent waiting at El Centro for their appointments and noted the excessive time and burdens they experienced in traveling to Havana for specialty appointments and accessing equipment or medications for their children.

Interestingly within both the interview and non-interviewed groups about 37% of the mothers indicated the need for help in the house. Smith (2003) refers to these experiences as the invisible activities of everyday life. The need for support services for individuals with disability and their families was identified as a priority during Cuba’s “social revolution.”

**Access and Utilization of Social Support**

Research has shown that mothers caring for their children with disability may display high levels of stress, and report feeling overwhelmed when they receive limited social support (Heltizer, Cunningham-Sabo as cited in McGuire, et al., 2004). The daily routines of the women interviewed in this study are strained by lack of material resources, limited availability and choices of accessible children therapy programs and infrastructure conditions associated with housing and transportation. Each of these factors contributes to maternal perceptions of burden of care as they mother their children with special needs. At the same time domestic and systematic, institutionalized social support
plays a decisive role in mothers’ emotional responses to caregiving and their ability to care for their child as they attend to themselves. In their qualitative study of women caring for young children with disability Olson and Esdaile (2000) found that mothering activities were compromised by deficient social support and macrosystem factors.

As noted earlier in this chapter, over 90% of the study sample reported family assistance in the care of their child. Most households consist of extended family members including grandparents, aunts and other relatives. In collective societies, families are expected to assist in the care of disabled family members and are often provided with social support to do so (Westbrook, Legge, & Pennay, 1993). However, most of mothers interviewed related enhanced perceptions of maternal burden of care with little discussion of the type and application of family support they received. These findings can best be understood by looking at Stack and Burton’s 1994 work on kinscripts.

Kinscripts is a framework that represents a view of how multigenerational collective families work out roles and responsibilities. Kinwork is one domain of the framework and is described as the labor that is expected of family members. Kinwork includes intergenerational care of children, economic survival, and networks of family extending beyond borders supporting the family through remittances. Kinwork is influenced by familial economic, physical and emotional needs. Structural factors also drive kinwork as observed during Cuba’s Special Period when extended families pooled resources and took turns securing food and household items. Similar to notions of the good mother, kinwork is viewed as superseding personal goals, and self-sacrificing with the objective of support and survival of the collective family.
I suspect that many of the mothers interviewed and surveyed in this study do receive caregiving support from their family, though during the interview most of the women did not directly report the sharing of tasks or everyday activities with family members. Instead they made references to the receipt of general help in the household. However the support received in caring for the child with disability takes on a less visible form as the childcare activities are embedded within the collective work of the family. As a result, the mothers may underestimate the amount of support they receive or may not be able to communicate the type of support they need in the care of their child as most mothers have no prior experience with a child with special needs. It is my view that the mothers in this study perceive that children with disability require a different form of family support in caregiving and that they are seeking institutionalized skilled social support services to augment the assistance they receive at home, though it seems that the mothers interviewed do not have the language to articulate or perhaps even comprehend the concept of home based skilled paraprofessional services as it is my understanding that Cuba’s health workforce does not include home health aides or therapy assistants.

Maria Isabel Dominguez, a sociologist and director of the Center for Psychological and Sociological Research in Havana, conducted an evaluation of the state’s achievement of social policy and programs introduced in 2000—the year that ushered in Cuba’s social revolution. Women and children, the elderly and individuals with disabilities and their families were identified as targeted social groups under this initiative. Coinciding with this historic project was the formation of Cuba’s first school of social work and the identification of disability as a national priority program. In her
assessment Dominguez found that although achievements have been made in Cuba’s social sphere, “development has not been systematically or comprehensively conceived.” This was most notably demonstrated by increased deficits in housing (Dominguez, 2009, p. 85).

Among the projects proposed in 2000, two current programs are aimed toward providing support services to children with disabilities and their families: social work evaluation of the needs of families in communities and services for individuals with disabilities, including economic support for mothers of disabled children. The School of Social Work has been successful in graduating cadres of social workers but limited in placing social workers into the community or institutions. El Centro de Rehabilitacion y Neurodesarrollo has requested the addition of a social worker to the staff, but due to economic constraints the position has not been filled. Consequently mothers whose children receive services at El Centro take on the responsibility of arranging transportation, negotiating the Ministry of Health to register their child as disabled, scheduling specialized medical appointments and identifying organizations or contacts that can assist them in getting medications or equipment needed for their child.

The women in this study typically access information and materials that they need through a “people-to-people” mechanism. When I asked the mothers during the interview process how they access the supplies needed to care for their children, one woman offered that since her mother works in tourism she will tell clients about the situation and they will make arrangements with organizations in other countries to get medications for the family. Others solicited the help of the Federation of Cuban Women and their
Committee for Defense of the Revolution. These organizations, however, were reported to provide little material support to the families. Jennifer indicated that when she needs something for her son she goes to social assistance. They have given her a television but she is still “fighting with them to get a refrigerator.” With the assistance of a neighborhood delegate, Jennifer just recently secured a wheelchair for her five-year-old son with severe disability.

Cuba does not have an institutionalized network of churches and charitable organizations that families can efficiently be referred to for material support. Through informal channels and word of mouth, some mothers have received donations of clothing, disposable diapers, and soap. One mother learned about a group of Christian brothers that helps families with disabled children through a neurologist in Havana. Over and over again Dr. Rodriguez and his staff assist the families in locating resources and acquiring medications. Brotherton (2008) in his analysis of individual health practices in Cuba’s current post-Soviet context brings together the state and its citizens in a system of “socios,” that is, personal connections that bridge the informal economy and state run institutions in efforts to acquire medical and health care resources. Physicians are integral players within this complex system as they provide individuals with accessible and specialized knowledge that points the Cuban consumer to the right socio connection. Brotherton argues that the capitalist based socio system has become institutionalized in Cuba as it “actively contributes to the daily functioning of Cuba’s socialist health care system” (p. 259).
Mothers who register their child as disabled in the Ministry of Public Health and meet evaluation criteria of dependency are entitled to economic support. If the disabled child attends a school or institution for any time during the day, the child’s mother will function as an assistant to the child and the teacher. Women with children with severe disability who used to work receive the equivalent salary they received in their job, maintain their benefits and retain their retirement (www.mujeres-cuba.co.cu). Essentially the women receive a stipend to enable them to care for their child full time.

While the intent of this policy acknowledges the hardships faced by mothers with children with severe disabilities, this practice also has the potential to reinforce women’s social isolation, place more burden on their daily routines and care for their child and at the same transfer the responsibility of skilled caregiving onto the mother. In effect, the policy appears to decrease maternal social support and increase maternal social and technical responsibility. A survey evaluating this program revealed that over 96% of women who participated were highly satisfied with the services. The survey suggested that more attention be given to assisting mothers in the organization of their children’s medical and rehabilitation services, stability in economic revenues and family interactions. I am not aware if any of the mothers interviewed participated in this program.

Cuba and in particular El Centro de Rehabilitacion y Neurodesarrollo have shown notable progress in the development of rehabilitation services and attention to individuals with disabilities. Dominguez (2009) asserts that Cuba is exploring new ways to promote the quality and effectiveness of social policy and development. She calls for a balance
between centralized and decentralized implementation of social programs that are holistic in conception and diversified in practice—a request for a new socialist approach that appreciates the diversity of group and individual needs and is informed by the collective and individual experiences of its citizens. Dominguez envisions an integrated macrosystem that appreciates interrelationships between health, economic and social sectors in promoting the well-being and development of Cuba’s people. This insight reflects and supports a principal tenet of Cuba’s health care system, that is, a community-based, family-centered biopsychosocial approach to health.

The interface between social support, material conditions and well-being emerged as each woman described and narrated her experiences of mothering a child with disability. Some of the experiences of the mothers whose children receive rehabilitation services in Cardenas are universal, such as notions of motherhood, and others are culturally specific. All of the women interviewed enjoy being a mother, welcome the love of their children and take pleasure in witnessing their children’s development. The notion of the good mother as the ideal of motherhood cuts across cultural boundaries and yet at the same time it is understood and enacted according to context specific cultural scripts. Cuba’s socialist, patriarchal, collective structure bolsters the model of the good mother through the codification of the family as the mother–child dyad and tacit expectations of allegiance to the nation’s revolutionary ideological principles and institutions. Cuba’s Special Period reinforced the good mother role as women were called on to sacrifice their self-interests not only for their families but also the collective society (Safa, 2009). In contrast to industrialized nations where a menu of domestic and professional support
services are often available, in Cuba, as well as in other collective societies, the family is expected to serve as primary caregivers for the elderly and those with disabilities (Westbrook, Legge, & Pennay, 1993). Cuba’s current socio-political and economic context considerably impacts how mothers of disabled children in this study access resources and navigate health and educational institutions. As described by Brotherton (2008), the informal economy has become an accepted mainstay in the daily lives of Cubans in search of medical supplies and medications, resulting in additional time and strategizing throughout the performance of daily activities and childcare.

Structural factors such as the organization of Cuba’s national health system and conceptions of disability also play a role in how mothers experience and perceive daily challenges in the care of their children. Cuba’s national health care system has just recently added components of rehabilitation medicine in the polyclinics and alerted community doctors to the needs of those with disability within their practice. The lack of paraprofessional or technical health positions within training programs and the health system limits opportunities to provide those with disabilities and their families with supportive services. Moreover, disability in Cuba is predominately viewed strictly as a medical condition despite efforts to adopt a social model of disability that acknowledges the role of structures and institutions in limiting the participation of individuals with disabilities. While these efforts are apparent at the community level, they do not permeate the organization of disability care or the mothers’ experiences. The medical view tends to perpetuate the hegemonic discourse of disability as tragic, assigning pity on the child and family. An outcome associated with the view of disability as pitiful is the selection of a
paternalistic charity-based approach that relieves those with disability of their contributive responsibilities to society while at the same time assigning stigma to the disabled child and mother of the child (DePoy & Gilson, 2004). Given this general perspective of disability and the structural factors that constrain access to material resources in addition to health and social environments, it is not surprising that the mothers in this study reported that their disabled child was their biggest challenge. Mothers in other social contexts might do this as well. Dr. Rodriguez and many of the mothers interviewed in this study contest the dominant discourse of disability and parts of cultural script that guides the good mother.

This portion of the interviews that explores notions of motherhood, daily routines and social support revealed minimal within-group distinctions. Most women enjoy motherhood and at the same time view their child with disabilities as their greatest challenge. The literature acknowledges this paradox of conflicting emotions that are experienced by women caring for a child with disability (Kearney & Griffin, 2001; Larson, 1998). The majority of the women interviewed described their routines as ordinary and compatible with the sociocultural context, though child intensive as they implied feelings of displacement and loss of personhood (Landsman, 2003; Wickham-Searle, 1992). Within-group differences began to emerge when mothers assessed if their motherhood experiences were similar to mothers caring for typically developing children. The women who reported that they perceived their experiences as different or about the same as mothers caring for typical children offered only time as a notable difference. Kellegrew’s (2000) study supports this finding. However, I would argue that time in
Cuba plays a significant role in all women’s daily lives, not only those caring for children with special needs, though women who mother children with disabilities within this sociocultural context are often impacted to greater extent due to economic constraints, lack of reliable transportation and invisible aspects of caring for children with special needs. The aftermath of the Special Period and the current Post-Special Period has been marked by scarcity of food and household supplies in stores, diminished monthly rations, and “being en la luchar”ii (Marrero, 2003) resulting in additional time to perform daily tasks.

As a visitor in Cuba, time was also not on my side. Each day I was required to develop and enact a scheme to get from the location of my accommodations to El Centro. I accessed the informal economy through people-to-people connections in order to obtain transportation to and from El Centro. On a few occasions, once it was clear that there was no ride in sight to get me where I needed to go, I quietly slipped onto a bus reserved for Cuban workers going to work in the hotels. I spent a seemingly enormous amount of time to convert money in a bank, as the line was long and very slow to advance. People would enter the line at different points as they indicated that had actually been waiting on line while they were sitting outside or on a couch in another section of the building. Food was scarce everywhere with the running joke—“What would you like for lunch? Ham and cheese, ham, cheese or cheese and ham?” It is difficult for me to imagine and fully understand given the current material conditions how challenging each day may be for each of the women who participated in this study. In telling their narratives, issues of 

ii Being in the struggle to procure items necessary for daily needs.
social support and institutional systems presented a significant backdrop to the activities of everyday life. The following chapter will elaborate on the approaches mothers adopt in acquiring resources for their children with disabilities, how they interact with institutional systems and health professionals as well as enactment of their agency within their situated context.
Elsa was asked about her vision for her son with disability. She responded, “to hope for the best, whatever is possible.” As noted in the above quote Elsa then went on to identify her hopes that her son would be seen as “normal” with a typical gait and living independently with a family of his own. Elsa had some difficulty responding to the next question that inquired what resources she would need to realize her vision for her son. After hesitation Elsa stated that she needed to finish her career “so that I can help him” and to have her own car so that she could bring her son to the center three times a week, indicating that transportation is “very hard.” Elsa offered that she can make a difference in her child’s life by giving him the best she can, providing support, doing the exercises and trying to “do everything I can.” She reported that the staff at El Centro always respects her opinion, and always offers assistance to mothers. Although Elsa feels that most of the time she can promote change in the community’s attitudes toward disability, she does not think that she can make a difference in her son’s progress.

Elsa’s agency in the care of her child is often constrained by the material conditions of her situated social context. However, cultural conceptions of disability and
behavioral expectations of women caring for their children with disability also contribute to how mothers engage in Cuba’s health care system and negotiate their roles within their particular context. The focus of this chapter is to present the variety of roles and arrangements mothers take on in navigating care for their children with disability and how they exhibit agency in their daily lives and within institutional structures.

Expressions of individual agency can be both overt and subtle. Agency is inherent in all individuals, though the form and expression of agency varies according to the social context and the elasticity of the social structures in which the individual is located. Social structures can constrain or enable collective and individual agency (Hays, 1994). While personal attributes or the particular socio-cultural context may indeed constrain an individual’s capacity to alter or transform events or conditions, all members of a society display some measure of agency in their daily lives (Sewell, 1992). This study borrows from Merton’s (1968) work on social theory and structure in its description and measurement of agency. Merton describes agency as types of behavioral adaptation within a particular cultural society. An individual’s adaptation patterns vary according to his acceptance of the society’s cultural values and institutional mechanisms to achieve his desired goal. In the context of this investigation agency is theorized and described as the types of patterns, strategies and responses mothers of children with disabilities employ from their unique location in the Cuba’s social structure. The roles that the mothers adopt in response to their situated realities are explored in order to uncover mechanisms that reproduce or transform culturally accepted modes of behavior and interactions in the care of their children with disabilities. However, demonstrations of individual agency in Cuba
can be challenging to uncover as collective forms of agency dominate the social landscape. During the course of this research data collected from the study survey, interviews and observations of mother and therapist interactions suggested that the women in this study responded to their children’s conditions, navigated institutional systems, acquired resources, participated in rehabilitation sessions and envisioned their children’s future in different ways. The strategies and behaviors mothers employed in the care of their children with disabilities seemed to be related to a certain form or expression of individual agency. These observations led to my formation of a typology that locates mothers within specific behavioral categories that describes the particular patterns, strategies and responses they use in every day care of the children with special needs. This chapter begins with presentation of the mother-therapist interactions to provide a starting point to identify the differing behaviors the mothers display within the clinical context. Interview data focusing on mothers’ visions for their children will follow to illustrate relationships between thematic findings and typology categories. Typology descriptions and profiles of the typology categories are then examined to identify the influence of sociodemographic variables on typology location and the forms of agency mothers within each category exhibit. Data collected from the study survey provides a foundation for understanding mothers’ perceptions of their roles in their children’s rehabilitation program.
Mother and Therapist Interactions

The research questionnaire completed by all of the 100 participants interviewed and non-interviewed participants indicated that the mothers of children with disabilities who receive services at El Centro generally agreed that the staff helped them understand their children’s condition, included mothers in therapy sessions and were receptive to the questions mothers presented. During the data collection phase of this project I spent time in the physical therapy gym as a participant observer. My role took on different forms according to the situational context. At times I quietly sat away from the focal therapy section observing general activities and interactions. On occasion I sat with the mothers waiting for their child’s appointment engaging in social conversations. The therapists would now and then ask me to assist with a child or solicit some suggestions during their sessions. Due to the unpredictable nature of the interview schedule, I did not assign specific time frames for observations in the gym. Though children are scheduled for therapy on specific days, they were not assigned a defined time slot for their session. Hence, I could not be certain which mothers and children would be available for observation at any given time. I documented my observations on the research observation coding form (see Appendix G) and in a notebook.

The observation coding form was used to document the frequency of social interactions between mother and therapist, mother/therapist engagement in the process and communication relating to the therapy session and child. Observations of the social environment and institutional procedures were recorded in the notebook.
The Observation Context

The physical therapy gym is a large, airy room containing therapy mats, therapeutic balls and devices, toys and a few small chairs to accommodate children or their parents during the session.

The waiting area is located right outside of the therapy gym in an open plaza that offers benches for children and families while they wait to be called into the gym. An open window that faces the waiting area allows families to view the ongoing therapy sessions and engage with the staff.
Typically the physical therapy staff sits along the rainbowed wall (See above). About six to eight therapists position themselves at the end of a therapy mat as the child receiving services is placed between the therapist and mother. The mother usually positions herself at the opposite end of the mat facing the therapist.

Children waiting for their appointments often wander into the room, mothers cluster to converse, and the space is often filled with the sounds of children crying. I had the opportunity to observe 10 of the interviewed mothers and their children during physical therapy sessions. I will present two of the families that I observed more frequently and then provide an overall impression of the social context and mother/parent interactions.
The Observations

I was able to observe Angelina and her daughter on three occasions in the rehabilitation gym. Angelina’s 16-month-old daughter is scheduled to attend physical therapy at El Centro three times a week. She shares a taxi from Matanzas with two other families. When I arrived in the gym every mat was occupied with therapist/child dyads. Most mothers sat at the end of the mat, others gathered by the entrance way talking. The room was noisy with a few babies crying. Angelina’s daughter was lying on her back on the therapy mat as the physical therapist moved her feet, then legs, trunk and arms. The child made a few sounds that the therapist imitated. Angelina was sitting on the edge of the mat keeping an eye on her five-year-old daughter as she observed the treatment regime of her toddler. Minimal interaction between the therapist and Angelina was noted. Neither the mother nor the therapist generated questions or commented on the child’s condition or response to the treatment. The therapist offered light social commentary relating to another therapist/child dyad two mats away. The therapist gestured to Angelina to hand her a piece of therapy equipment. Angelina retrieved the equipment and remained quietly observing the session. Both mother and therapist were distracted by the other activities in the gym. The therapist engaged in conversation with the therapist sitting next to her and mothers waiting for their children’s appointments. When the forty-five minute session was completed the therapist picked up the child and handed her to her mother. Angelina did not ask any questions, carried her daughter to another part of the gym and got her daughter ready for the taxi ride home.
Ivette lives in Cardenas with her son who is six-years-old. She is a single mother. Ivette was observed waiting for a therapist to be available for her son. Her son has severe disability. While waiting Ivette placed her son on a mat and began moving his arms and legs in a manner similar to the activities the therapists perform. Other mothers came over and talked to Ivette. They mothers acknowledged Ivette’s son with social greetings. Ivette had a bag full of toys for her son and pulled out a toy to present to him and stated that her son liked the musical toys the best. Ivette waited for the therapist to call for her son for approximately one hour. During her wait she circulated throughout the room, checked on the other children receiving therapy, ate breakfast and cared for another child when his mother stepped out of the gym. When the therapist was ready to begin Ivette’s son’s treatment he gestured to Ivette to bring him to the mat. Ivette initiated the greeting and laid a blanket on the mat placing her son on top of the blanket lying on his back. She then got up and brought a small bolster and placed it under her son’s neck for support.

While waiting for the therapy to begin, Ivette pulled a red ball from her bag and gently rubbed her son’s arm with the ball. The therapist began to exercise the child’s leg. Ivette interrupted to indicate that her son had an eyelash on his eye and asked the therapist to remove it. The therapist brushed away the lash and resumed exercising the child’s legs. Ivette took some musical toys from her bag and presented them her son as he was being exercised. The child began to cry and Ivette requested that the therapist stop performing the exercises. The physical therapist declined her request. The child became more upset. Ivette and the therapist then worked together to calm the child. Throughout the treatment session Ivette initiated conversations, asked questions relating to the
therapy session, engaged her child during the activities and manually assisted the therapist in changing her son’s position. Ivette also communicated her observations of her son throughout the session to the therapist. The therapist did not offer his observations during the session or pose any questions to Ivette. He did minimally initiate casual conversation. Both Ivette and the therapist at times diverted their attention to other activities in the gym. At one point several of the therapists working with other children teased Ivette about her stylish clothing and accessories. The treatment session ended with the therapist stating, “we are finished,” and walking away from the mat. Ivette then picked up her son, moved to another location in the gym, gave her son lunch, changed his clothing, socialized with other mothers and then left the gym about 45 minutes after the session ended.

The physical therapy staff at El Centro is bright, cheerful, active, and congenial. Therapists with valued experience and Dr. Jorge Rodriguez oversee the young staff. In general during the treatment sessions, the younger staff tended to be limited in their attempts to engage the mothers in the therapy session, minimally posed questions to the mothers or offered their observations. They were rarely observed to instruct the mothers in activities to support their children’s development. The organization of the physical therapy gym space, that is the alignment of mats and staff in a cluster, appeared to promote distraction and facilitated social conversations between therapists during sessions. As I was observing the mothers’ interactions with each other I began to sense and overhear conversations that suggested that mothers not only had differing ways of
positioning themselves in the therapy gym, and engaging in the treatment process but they also had varying expectations and visions for their children with disabilities.

Mothers’ Vision for their Children with Disabilities

The literature (Landsman, 1998; Fisher & Goodley, 2007; Kearney & Griffin, 2001; Milo, 1997) has shown that when informed of their child’s disability mothers often find meaning in parenting children with disabilities and let go of the child they had hoped for by constructing new narratives and wishes to accommodate their child with disability. When asked about their vision for their children with disabilities mothers in this study provided a diversity of responses, ranging from “whatever God wants” to “I would like to see her as a dancer” and “I can’t tell. It will take time.” How women approach their children’s disability appears to be connected to the visions they hold for their sons or daughters which in turn may be strongly related to their level of knowledge and understanding of the disability, social support and resources. Themes that emerged during interviews included the child’s inclusion and acceptance into the community, participation in school, development of physical skills and socially beneficial qualities. Belkis stated that she would like her two-year-old granddaughter to “be walking very good. Use her eyes very well. To have no dysplasia.” She goes on to emphasize the import of her wish, “I have a lot of faith. I believe in God and I ask God everyday for the benefit of the child.” Jennifer is the mother of a five-year-old boy with severe cerebral palsy. He is unable to hold his head up, sit alone or move from one position to another. He is non-verbal and his cognition is undetermined due to his physical disability that
limits his ability to perform any functional activities, engage in play or learning activities. Jennifer quietly utters, “I wish he could at least walk. I keep wondering when he will walk.” Many of the women interviewed, about a quarter of the interview sample, identified walking as their hope for their children. Standing and walking has significant meaning for these mothers. As observed by McKeever and Miller (2004) upright positioning and walking can provide the child with disability an appearance of normalcy, reducing the stigma of their condition and permitting enhanced opportunities for social recognition and interactions. It may also provide the mothers with a mechanism to gain more confidence in their role and access to resources as their child’s upright position signifies their child’s personhood and reinforces a woman’s position as a mother.

Several women indicated qualities or characteristics they would like their disabled children to have. Desired attributes included to be independent, to be smart, talk a lot, to be a good boy, to be normal and “to try to be a person who is as normal as possible.” The notion of normalcy was a recurrent topic throughout the interviews. Mothers brought up the matter of normalcy when asked about their vision for their children, how they feel about their children’s conditions at the present time, how they explain their children’s conditions to others and their experiences of motherhood. These references to normalcy may reflect a mother’s rejection of the dominant views of normalcy within the culture and hence allow her to view her child and his or her condition and her experiences and agency within the continuum of normal (Fisher & Goodley, 2007). Alternatively, the mother may seek the identification of her child as normal because of institutional attitudes toward disability and constraining conditions within the social structure that
assign stigma to both the child and mother (Hughes, 2002). This latter explanation suggests that these mothers may be in “denial” about or not understand the extent to which their children are disabled. They can only envision a future in which they return to or regain a sense of normalcy. Given that 54% of the women who participated in the study survey responded always that the community has a positive attitude toward disability and only 36% of the surveyed mothers reported that always they can make a difference in changing attitudes toward disability, it is my impression that the women in this study identify their children with disabilities as normal to counter stigma and tacit constraints that may impede their children’s participation in social and educational contexts.

Fifteen of the 34 mothers envisioned their children with disabilities participating in school. Aspirations ranged from the desire to have the child go to a special school, to learn, to get a university degree and to be capable of making his/her own decisions. Again, the issue of normalcy was brought up. One respondent offered, “I would like him to go to school and develop like a normal child.” Another mother stated her vision for her daughter was to go “to school like a normal kid.” Miriam hoped that her seven-year-old grandson with attention deficit disorder can study, “reach every grade, progress,” though she worried about his discipline in the classroom. In her response Mayra displayed her knowledge and understanding of the educational system in providing services to children with special needs. She shared that research conducted in Havana indicated “that teachers in normal schools need more orientation on how to deal with these kids, but I know that they don’t have enough time for these [special needs] kids. I know the professional
program [teaching] is very fast.” Mayra’s son is 10-years-old and she wants him to learn. Yet she remarked, “It depends on him, the interest he has. I explained to him that he needs dedication for what he wants to do.”

Inclusion of children with disability within Cuba’s educational system is an emerging and developing process. Dr. Rodriguez has been instrumental in promoting the integration of special needs students into their community schools. As indicated by the above responses close to 50% of the mothers interviewed in this study view schooling as a principal goal for their children. Only a handful of the women, however, demonstrated fundamental understanding of the workings of the educational system and how to approach the inclusion of their children. The availability and distribution of the information and resources mothers need to place their children with disabilities in school appears to be lacking or underdeveloped at both local and institutional levels.

Dr. Jorge Rodriguez’s vision for children with disabilities in Cuba is full integration into social and academic life. This vision is shared by a few of the mothers whose children receive rehabilitation services at El Centro de Rehabilitacion y Neurodesarrollo in Cardenas, Cuba. Theresa’s vision for her son is that he is not stopped because of his condition, “not to be stagnated by his disability.” Luz feels that her son has the personality to be integrated. “I would like him to be integrated into the community. I would like him to be a sports player.” One mother also indicated that she would like her daughter to be included in community programs, to place her in a dance class. Sara simply stated, “I want my child to be integrated into the community.”
Participation of children with disabilities in social, cultural and academic environments is an evolving concept in Cuba. El Centro has begun to explore the adoption of a social model of disability to replace or augment the widely accepted medical model of physical impairment. Dr. Rodriguez is promoting this model in an effort to expand mothers and families’ view of their children with disabilities. The social model counters disability as tragic and instead recognizes the role of structural ideologies and institutional arrangements in enabling and constraining the daily lived experience and full participation of those with disabilities within the sociocultural context. The social model also takes into account how institutional arrangements and material conditions prevent or promote the vision and hopes families hold for their children with disabilities. How then does Cuba’s structural framework affect the aspirations mothers maintain for their disabled children? Moreover what do mothers in this study need to realize their vision for their children with disabilities and how can they access what is needed? This was a surprisingly difficult question for the women in this study to answer.

**Realizing the vision**

The Cuban revolution was founded on the principles of distributive equality and has provided its citizenship with free access to health care, education and monthly food rations. Dependency on the state, limited access to information and blurred boundaries between the state and individual responsibility (Krull & Kobayashi, 2009) may contribute to the finding that in general and particular to this study’s context of disability, that a number of mothers seem not to know what they needed to support their visions for the
children with disabilities. Limited understanding of their children’s capabilities and the type of supports that are needed to promote integration of their children may be explained by the lack of collective knowledge relating to disability and mothers’ inexperience in caring for their children with special needs. Many mothers rely on El Centro to identify the needs of their children and report having difficulty employing effective strategies to procure the resources and support they need to actualize their vision for their children. This portion of the interview asked mothers what was needed to realize their vision for their children. Responses offered by the interviewees included: doing the exercises, procuring resources, parent training, the reduction of stigma and spiritual or social support. When mothers were asked what they could do to attain their dreams for their children responses were mostly limited to doing the exercises and being a good mother. When positioned next to the survey finding that 66% of mothers felt that they could always make a difference in their children’s progress, it appears that many of the women may feel capable in assisting their children and yet may not have an effective way to go about it. The interview questions that surround the topic of vision emphasize the disjunction between the abstract conception of agency and the behaviors the mothers adopt within their constrained and situated realities.

According to Krull and Kobayashi (2009) women in Cuba have historically come together as a model of collective agency in response to the hardships they experienced during times of material shortages. Collective agency is postulated to be the dominant and clearest manifestation of actions directed toward changing societal structures in Cuba. The Special Period underscored the collective struggle and action of all Cubans in
acquiring resources and developing strategies needed to navigate the new and uncertain social and economic systems. Drawing upon Hays’ (1994) work on structure, agency and culture, the historic circumstances of the Special Period may have provided a space for unintentional though transformative change that in turn advanced enactment of individual agency as Cuban citizens began to make choices from a wider range of structurally available possibilities. The nation’s economic crisis resulted in women taking on greater responsibilities as they navigated the informal economy to obtain household and medical resources for their families (Toro-Morn et al., 2002). Cuba’s surge of socio activities coupled with limited state surveillance of the informal economy provided opportunities for individual agency as citizens applied successful schemes developed during the Special Period to access new avenues of material distribution. At the same time the Cuban dual-dollar economy—that is the Cuban peso and US dollar introduced during the Special Period, along with its current version, the Cuban peso and the convertible peso—has resulted in economic stratification. This further challenges the collective ideology and collective agency. One outcome of these new methods of material acquisition is the stratification of individuals by “culture,” signified by their access to dollars, educational opportunities and informational networks.

The first time I heard the term “culture” used as a descriptor of a specific group was during Fidel Castro’s remarks at the School of Social Work in 2002. As noted in the opening chapter, President Castro was presenting his concept of the “social revolution” aimed at improving the nation’s social conditions such as school truancy, disability and services for older adults. Through a survey of Cuba’s social problems, a relationship was
found between the family’s “cultural level” and their children’s performance in school and participation in criminal activities. These findings led to the categorization of families and individuals according to cultural status, that is low or high culture.

The state’s description of a family of low culture included divorce, low parental educational attainment and low socioeconomic status. In essence the term “culture” may be viewed as a proxy for class. It is my impression that the term culture rather than class was chosen to describe one’s location within society, not because class can be a messy construct, but because the notion of class is contrary to the principles of a society grounded in distributive equality and social justice. A primary objective of Cuba’s 2002 social revolution was for the social work students to intervene with the families of “low culture.” The difficulties of the Special Period widened the previously unspoken class gap in Cuba and opened the door for distinct differences in the everyday experiences of Cubans. This change in social arrangements and status was increasingly evident when I returned to Cardenas in January 2009 to begin this project.

During my observations in the rehabilitation gym and the interview process I began to notice that differences in educational level, geographic locations, and access to resources distinguished the women in the ways they approached their children’s disability, their relationship with El Centro and staff, their involvement in the rehabilitation process, their visions for their children and the agency they exhibited in the care of their children. Distinctions in “class” and access to material resources were apparent and seemed to strain the collective ideology. On the day this project was initiated the woman who provided interpretation and translation during the interviews
was immediately identified as a Habanita\textsuperscript{iii}, as a few individuals commented on her style of clothing, quick pace and obvious high educational level and skill. On occasion, staff would offer unsolicited social information to indicate that the mother being interviewed was challenged by her social circumstances or lack of education, while at the same time acknowledging the admirable efforts the woman had demonstrated in the care of her child. These interactions and observations during the interviews raised my interest in the notion of “culture” within this research project and local environment. It was my impression that there were distinct differences in the ways women in this study were situated in the rehabilitation context, obtained resources, understood and made sense of their children’s conditions and worked within and outside of institutional structures. I then developed a working typology of the mothers to evaluate possible associations between mothers’ attitudes, practices, forms of agency and their location within a “cultural” typology. I classified the mothers’ responses and approaches to the care of their children with disabilities as: the provincial mother, the community mother, and the cosmopolitan mother.

It is of note that all of the women who participated in the interviews can be described as having attributes common to the cultural script of the “good mother.” It was my observation that all of the women interviewed were devoted to their children and took loving care of them. As previously discussed in the chapter on motherhood, the good mother is a specific cultural script in Cuba that provides a framework for gendered and

\textsuperscript{iii} Habanita—a resident of the city of Havana, stereotyped as cosmopolitan with access to resources, not a country person.
institutional expectations of women with children. Though slices of the good mother script are scattered throughout the typologies, the provincial mother role clearly embodies and adapts the good mother ideal to the rehabilitation context. The typology categories were selected to describe and convey the mothers’ unique and situated location within the social structure. Even though distinctions in social or economic class in Cuba are at times difficult to define, variations in educational attainment, geographical locations, and scope of social capital play a role in classifying individuals into sub-groups.

The terms community mother and cosmopolitan mother were developed to illustrate the geographic and symbolic scope of the women’s social location. The provincial mother’s domain is centered in her local town. In the case of this study, the town is Cardenas. The community mother’s *habitus* extends beyond her hometown into neighboring surroundings. The cosmopolitan woman is as comfortable in Havana as she is in her neighborhood. I also found it necessary to add a fourth category that acknowledged the women who care for their child with disability though have limited engagement in the rehab process. The three women who are located in the remote mother category conveyed a detachment from the rehabilitation process. Each presented with flatness in their short responses. One mother had just returned to El Centro with her son after a three year absence. Following is a description of the criteria used to locate each woman interviewed in one of the typology categories (Table 7.1).
### Table 7.1

**Typology Descriptions**

<table>
<thead>
<tr>
<th></th>
<th>Provincial mother</th>
<th>Community mother</th>
<th>Cosmopolitan mother</th>
<th>Remote mother</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mother’s Self Identity</strong></td>
<td>Strong identity as a mother, displaces personal interests</td>
<td>Strong identity as a mother and identifies personal interests</td>
<td>Strong sense of self as a woman and mother, identifies and pursues self interests</td>
<td>Minimal identification with role as mother, does not identify self interests</td>
</tr>
<tr>
<td></td>
<td>- I am devoted to my child</td>
<td>- I am committed to my child</td>
<td>- I am not shy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- I have no time for myself</td>
<td>- It is my responsibility</td>
<td>- I ask a lot of questions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- It is my responsibility</td>
<td>- I want to go back to work</td>
<td>- I go out dancing</td>
<td></td>
</tr>
<tr>
<td><strong>Patterns of Acquiring Resources</strong></td>
<td>Seeks resources locally through informal networks</td>
<td>Seeks resources beyond local town through formal and informal networks</td>
<td>Seeks resources through a variety of approaches formally/informally inside and outside of local network</td>
<td>Limited seeking of resources</td>
</tr>
<tr>
<td></td>
<td>- I talk to the other mothers</td>
<td>- I took my child to Havana</td>
<td>- I used the internet to get information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- A friend told me that I …</td>
<td>- I went to the FMC for help</td>
<td>- I approached non-profit organizations</td>
<td></td>
</tr>
</tbody>
</table>
The different behaviors, roles and characteristics that mothers present in the care of their disabled children make up the cultural typology categories. Eight of the 34 mothers were identified as cosmopolitan mothers, nine women were located in the community mother category and 14 mothers were assigned to the provincial mother typology. As previously mentioned three of the women who care for children with disability were identified as being remote mothers.

The majority of provincial mothers have a child with disability between one and two years of age. Most of the community and cosmopolitan mothers care for a child between the ages of three and five years. It would be fair to hypothesize that mothering a

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iii The remote group of mothers included three women. Their responses to the demographic profile will not be discussed due to the small representation of women and inconsistency in responses.
younger child with disability may be less burdensome to the caregiver and as such afford
the mother a certain approach and perspective in the care of her disabled child. Conversely the argument could be made that mothers gain more experience in their
caregiving role as their children age and thus may reconstruct their attitudes toward
disability. However child’s age does not influence the location of the women in the
typology categories. The majority of women in each category reported their age as
between 30 and 39 years. This age cohort is of interest as it captures the social generation
that came of age during the Special Period\textsuperscript{liv}.

Krull and Kobayashi (2009) found that women between the ages of 18 and 44
years identified the Special Period as the most important Cuban event. Women over 50
years of age named the Cuban revolution as the pivotal Cuban experience. The
researchers noted that the experiences of women who came of age during the economic
hardships of the Special Period and without shared memories or ties to the Cuban
Revolution approached life from pragmatic or disengaged perspective. They were also
more likely to openly discuss national social problems. Accordingly, women’s
generational location and life course may indirectly shape their attitudes toward
institutional structures and their functioning within and outside of the system. The
women interviewed in this study do reflect the attitudes and behaviors found in Krull &
Kobashayi’s study. The mothers located in the cosmopolitan category articulated a
pragmatic approach to the care of their children whereas the community mothers

\textsuperscript{liv} Social generation—given generation in their formative years (18–25 years) during a
destabilizing period of change and hardship.
suggested a sense of disengagement with social processes. Once the cultural typology was constructed and the interview group was placed within relevant categories, I examined survey and interview data to evaluate if any associations existed between demographic variables and the location of the women within the cultural typology.

The majority of women in each category reported their child’s diagnosis as a neurological condition. Slightly over a quarter of the provincial mothers indicated their child was identified with a developmental condition. This finding can be explained by the provincial mothers’ higher percentage of caring for children below the age of three years. It is not uncommon for children with disability to not receive a final diagnosis such as a neurological condition until after the age of two years.

Women’s educational, marital and work status were found to be related to the assignment of women within a particular category. Women identified as being “cosmopolitan” are the most likely to have a university degree, to be married and the least likely to work outside of the home. All of the cosmopolitan mothers reported being married. The “provincial” mothers are the least likely to have a university degree and the most likely to work, with 79% reporting being married. The “community” mother is the least likely to report being married, with 44% of these women holding a university degree and one-third of this group working outside of the home. None of the mothers identified as “remote” have a university degree or work outside of the home. Only one of the three women in this category reported being married.

Consideration of cultural level or class is useful in explaining the location of the mothers within this study’s typology. Child’s age, child’s diagnosis and mother’s age do
not appear to explain the women’s situated position within the given typology. The majority of women in the interview sample can be considered to have a worldview shaped by their experiences during the Special Period, as the time of severe economic crisis occurred during their formative years of 18 to 25. Nonetheless, as noted by Krull and Kobayashi (2009), Mannheim pointed out that although generational cohorts may share the same historical experiences, individuals may view events in varying ways due to their class, race or gender. Geographical location may in part influence women’s approach to the care of their child. Cosmopolitan mothers are more likely to reside in the city of Matanzas, provincial mothers tend to live in Cardenas and the community mother is most likely to come from the countryside, in Limonar. Yet geographical location can certainly be as indicative of class/cultural level. Cuba’s description of cultural level takes into account the level of educational attainment, marital status and socioeconomic status. For the purpose of this study, a woman’s work status serves as a proxy for socioeconomic status. Nazzari (1983) noted that the primary reason for a Cuban woman to work outside of the home was either due to divorce or the inadequacy of her husband’s salary. As Cuba does not report individual or family income, women’s participation in the workforce may be the only indicator available to distinguish income levels, though women’s employment may enhance a sufficient household salary or fill the gap of monthly expenses. Still it must be noted that monies received through oversees remittances, the tourism sector, and other avenues outside of institutional structures clearly contribute to individual and family socioeconomic status.
Though not openly or formally recognized, race is a quiet contributor in the designation of an individual’s cultural level in Cuba. Afro-Cubans are rarely employed in the lucrative tourist industry, and only five percent of Afro-Cubans receive remittances from relatives abroad (compared to thirty to forty percent of other Cubans) and thus have limited access to American dollars required for participation in the informal economy and certain economic sectors (De la Fuente, 2007). How then do cultural differences contribute to the actions and agency mothers of children with disabilities exhibit in the care of their children and their attitudes toward disability and rehabilitation services?

Typology and Mothers’ Attitudes toward Rehabilitation Services

Examination of the interviewed mothers’ responses to the research questionnaire administered to all one hundred participants in this study are helpful in supporting the typology categories and distinguishing attitudes common to all mothers and those that differ according to typology. The research questionnaire elicited maternal attitudes toward rehabilitation services, professional staff, and mothers’ ability to effect change. Study participants were asked to indicate their level of agreement with ten statements through use of a Likert scale with response choices of no, most of the time or always.

Within the typology categories the provincial mother group was the most likely to always agree with each of the survey statements with the exception of being comfortable asking questions. However, this finding is of limited value as ninety-three percent of provincial mothers always agreed with this statement. All of cosmopolitan mothers always agreed that they were comfortable asking the staff questions.
The community mothers were the least likely to agree with survey statements related to rehabilitation service delivery and professional interactions. This group demonstrated the lowest percentage of agreeing that the center always offers the needed services, always offers support to the mothers, always helps the mother understand her child’s condition and that the mother is always comfortable asking questions and included in therapy. On the other hand, the community mother is the most likely to respond that the community always has a positive attitude toward disability.

In contrast, the cosmopolitan mother is the least likely to respond “always” to survey statements that speak to attitudes, agency and access to information suggesting that these women are more discerning and critical in their survey responses. These statements include: the center offers parent education, the staff respects my opinion, mother can make a difference in her child’s progress, the community has a positive attitude toward disability and mother can change attitudes toward disability. All of the mothers in the remote category responded always to each question suggesting their detachment or poor discrimination during the survey process.

These results suggest that cultural or class distinction are associated with the mothers’ attitudes toward the services provided at El Centro, perceptions of their own agency and societal attitudes toward individuals with disabilities. Building upon Krull and Kobayashi’s (2009) within-group variations of Cuba’s Special Period generation, the interviewed sample tended to engage with institutional structures and arrangements from differing sociocultural perspectives. Merton (1968) holds that variations in cultural values and role behaviors can be attributed to the different positions individuals occupy within
the social structure. The provincial mothers remain loyal to the vision of the collective and traditional ways of interacting with institutional systems, professionals and accessing services. The women located in the community mother group tend to be more questioning of institutional mechanisms, seek alternative ways to acquire resources and appear to be less engaged in supporting the vision of the collective society. The cosmopolitan mothers understand the need for new forms of social interaction and ways of thinking. Their vision is supported by their skill in accessing information and resources allowed within the social structure. They are faithful to the collective, though pragmatic in their approach. The following vignettes provide a portrait and insight into the three categories that women mothering their children with disabilities in this study occupy.

The Provincial Mother. Rosario is 38-years-old. She lives in the province of Matanzas with her husband, her 11-year-old son with hemiplegia and the child’s grandmother. She has completed a polytechnical program. Rosario can identify her child’s diagnosis, and states “I understand the condition and I accept it. I never asked myself why. It is here and I have to deal with it.” Rosario’s son was diagnosed at birth with asphyxia. She recalls feeling traumatized, “it was very hard, it was a hard moment.” At the time of her interview Rosario stated that “now I am more calm.” She also viewed her son as normal and progressing every day.

Rosario’s vision for her son is to “help him every way I can. He decides what he wants to do and I will help.” When asked about what she would need to achieve her vision Rosario replied, “I don’t know what to say.” With prompting she offered, “transportation is helpful, it is hard to get here.” Rosario views her role in realizing her
vision for her son is to do “everything that the doctor said.” Rosario believes that most of the time the community has a positive attitude toward people with disabilities. She strongly agrees that she can make a difference in other people’s attitudes towards children with disabilities and in her son’s progress.

The provincial mother when compared to the other typology categories is more likely to identify exercise and following the directions of the doctors and staff at the center as what is needed to meet her aspirations for her child. Yvelisse’s vision for her daughter is for her to walk and be as “normal a person as she can be.” In order for this to occur Yvelisse asserts, “this clinic should never disappear. I love everyone in this clinic. They are like a big family to me.” Nancy also relies on the clinic to meet her vision for her child. “I need to continue with the exercises. The child needs to be continually treated by the doctors.” Juanita, the mother of a young girl with Down Syndrome, commented, “Sincerely we need nothing. I have the help of my husband.” Carmen also referred to the support she receives in her response, “He has everything. I bring him here [El Centro] everyday. He gets good medical services and everyone is concerned.”

When the mothers were asked what they could do to achieve their vision for their children without exception the women in this category responded either doing the exercises or bringing their children to the center. Thelma lives in the countryside of Matanzas and brings her son to El Centro everyday she can. For three years Thelma would hitch hike with her son to Cardenas. In her response to the question about her role in promoting her vision for her son Thelma said, “I do the exercises, keep coming here.
Even when I was at home for three days because of no taxi, I did the exercises, called the taxi and told them that I needed the taxi for my son.”

The provincial mothers are most consistent with the mainstream ideology, viewing their children’s disability from a medical perspective. They put their faith in the staff at El Centro and follow prescribed exercise regimes. Their vision for their children is somewhat reductionist and also grounded in an impairment based model of disability. Most of the mothers who occupy a position in this category voiced that their vision for their children is the attainment of a specific physical skill, particularly walking. This group tends to view disability from a bipolar perspective of able/disabled as they minimize their children’s condition to others and are more likely to present their children as normal. The provincial mothers are the least likely to have a university degree. They clearly respect the work of the staff at El Centro, most report that El Centro is like being with family. They are devoted to their children often putting aside their own interests.

The provincial mothers utilize strategies and responses that are similar to Merton’s (1968) behavioral adaptation mode of conformity. According to Merton, mothers who conform to society’s expectations value both the cultural goals of the society and the prescribed institutional mechanisms to attain desired goals. The provincial mothers mainly function within institutional boundaries and their local milieu. These mothers are also awarded social approval from therapy staff as they adapt the good mother cultural script to the rehabilitation environment. Similar to Merton’s conformist individual, the provincial mothers maintain the stability and continuity of the society. The type of agency or adaptive behaviors these mothers demonstrate can best be identified as
structurally reproductive agency, that is exhibition and reinforcement of individual actions that are sanctioned and institutionalized by the state (Hays, 1994). This form of agency serves the mothers and their children well as it is compatible with the shared values in their situated reality.

The Community Mother. Belkis lives with her family in Limonar, in the countryside of Matanzas. Her family includes her husband, three-year-old daughter and 11-year-old son. Belkis’ parents live close by. Belkis is 33-years-old and has completed a pre-university program. She describes her three-year-old daughter with spastic diplegia as spontaneous, smart and difficult at times. Belkis found out about her daughter’s condition when the child was nine-months-old. Belkis shows a clear understanding of her daughter’s diagnosis explaining it as “a brain lesion that would not get better or worse.” When others ask about the child’s disability Belkis “just explains it to them. I tell them it is neurological.” Belkis has taken her daughter to Havana for further evaluations and consultation. Belkis envisions her child doing things for herself and walking. To attain this vision Belkis exercises her daughter and “gives her everything.” Belkis acknowledges that she faces limitations in support of her child as only her husband works. She would like to have equipment for her home “like having parallel bars.” Belkis has reached out to family in the United States. Her family has sent a therapy ball and a stroller for her daughter. A community friend referred Belkis to a wheelchair organization though she was required to belong to the organization in order to receive equipment for her daughter. Belkis thinks that most of the community has a positive attitude toward those who are disabled. When asked by survey if she could make a
difference in people’s attitudes towards disability and her daughter’s progress Belkis did not respond to these two questions.

Belkis’ narrative reflects the tension some mothers experience in not knowing what supports or resources are available or how to efficiently access needed resources. The community mothers are the most likely to indicate that they did not need anything to meet their vision for their child with disability. Sonia recognized the contributions of El Centro and family in her statement, “I need nothing. I have all the attention of the clinic, very good technicians… I have family support.” Fatima also indicated that she did not know what was needed to achieve her vision of her son walking and attending school. Fatima’s response suggested her resignation to an institutional structure she sees as limited. “I don’t know. I am not sure a school will take him, but it is up to me to be on top of them. I gave up trying to get a taxi, they are not reliable. I went to the Ministry of Health, Committee for the Defense of the Revolution and Federation of Cuban Women. I received no support.”

The community mothers reflect the atmosphere of Cuba’s current transitional state signified by the transfer of power from Fidel Castro to Raul Castro in 2008. This is a time of blurred boundaries, economic uncertainty and uncharted navigation of Cuba’s evolving market-friendly socialist structure as the nation is again confronted with economic hardship. The mothers in this group occupy a middle ground between the traditional provincial mothers and the sophisticated cosmopolitan mothers. The community mothers are spirited and spontaneous in sharing their appraisal of the Cuba’s current economic and social context. One mother freely stated, “Fidel talks a lot about the
disabled kids. In my case I have not seen it.” She continued, “It is my opinion that the schools do not give attention to the children with disabilities.”

Other remarks shared by mothers located in this category included:

“I want the clinic to be open to more to people. I want there to be direct access.”

“People-to-people [information sharing] is not very organized, not coordinated.”

“Practically I cannot do things at home, to have equipment at home I have to employ a carpenter.”

“Things are difficult here, there is supposed to be an organization for kids, I don’t know the name.”

Similar to the provincial mothers, some community mothers have a limited perspective as to what they can do to support their expectations for their children with disabilities. Several of the women defined by this typology indicated performing the exercises and seeking services at El Centro as what they could do. Other women in this group couched their responses relating to what they could do to realize their vision in the script of the good mother. Sonia replied my job is “to support my son, maybe to influence, to be insistent, to push. I want my son to be proud of his mother.” Elsa offered that she tries to find things that are helpful to her son.

Most of the community mothers report some discomfort with the El Centro staff. When compared to the other typology categories these mothers are the least likely to agree that the staff at El Centro is helpful in supporting mothers by including them into the therapy session, answering questions or assisting the women in making sense of their children’s conditions. However, this group of mothers is the most likely to accept their
child’s diagnosis without explanation, perhaps suggesting a challenge to the medical model of disability. Community mothers are the most likely to report that at the time of their interviews that they felt better about their children’s diagnosis. Most of these women envision their children attending school and at the same time acknowledge the material and structural obstacles to their dream. The community mothers are dedicated to their children and employ a variety of strategies to obtain information and resources, though they are at times inefficient or unsuccessful in their attempt. In contrast to the provincial mothers, this group, through their seemingly uncensored and forthcoming analysis of current conditions as they challenge traditional institutional arrangements and interactions, potentially can pave the path for structurally transformative agency.

When viewing this group from Merton’s (1968) thesis on the relationship between role behavior and situated realities an attenuated version of Merton’s innovator typology can be applied to the community mother. The innovator demonstrates allegiance and compliance with societal goals yet does not value the institutional norms established to attain the goal. In other words, the community mothers seeks resources and services outside of defined institutional arrangements. Merton suggests that innovators take on this role in situations where there is a lack of opportunities within the structure to access resources and dissatisfaction with the state due to its inability to meet individual or collective needs. The innovator is not awarded the social approval assigned to the conformist. During my observations in the physical therapy gym, many of the community mothers were the women that the staff indirectly complained about or made comments suggesting disapproval. Though the type of agency community mothers exhibit may not
confer institutional benefits, it is effective in new formations of social networking and accessing information.

The Cosmopolitan Mother. Sarah is married, has attained a university degree and is now studying to become a defectologist. She is 37 years of age. She has a two-year-old daughter with Down Syndrome and a 15-year-old son. The family lives in the capital of Matanzas. When Sarah’s daughter was born she expressed happiness and sadness, stating “I knew it would be a problem for life.” Sarah describes her experiences as a mother as, “challenges are a lot… never ends even if they are healthy. I try to make time for everything. I enjoy music, going out. We know she has some problems, but we do not pity her for it.” Sarah goes on to say, “To me she is normal. Of course we provide her with special things that she likes. We always provide constant attention to her, if not she will not progress.” At the time of the research survey, Sarah indicated that she always feels that she can make a difference in her daughter’s development. When Sarah’s daughter was diagnosed, Sarah and her husband immediately began to get information, read books, and did research on Down Syndrome. Though she expected “to have a normal child” Sarah adapted her vision for her child and includes her daughter in every family and community event. Sarah would like to see her daughter attain her highest level of development, attend school and be integrated into the community. She seeks family education and training to meet her vision for her daughter and a “taxi regiment” to improve access to services. Sarah offers that most of the time she thinks that she can promote change in people’s attitudes toward children with disabilities.
The women located in the cosmopolitan category indicated the need for practical, material resources as well as intangible assets to actualize their vision for their children. Velma stated that she needed help to get medications. She also indicated that her son needed training for activities of daily living. Marta recalled, “I have asked my husband’s work for a house in Cardenas to be closer to the center, I have asked for a salary from the government.” Theresa requested to have therapy equipment and a computer in her home and the “tools” to develop her son physically and intellectually. Elena valued asking lots of questions and asking for guidance as being most helpful in achieving her expectations for her son. Mayra acknowledged the stigma society attached to her and her child and called for the “comprehensive understanding of people who have to deal with him.” The women in this category presented varied responses to the question what can you do to realize your dream for your child. Two of the eight women in this group offered continuation of the rehabilitation program at home and exercises as important. The other mothers identified taking an educational course, approaching social workers and other health professionals for services, participating more fully in the child’s rehab program and engaging in research.

The cosmopolitan mothers demonstrate a more nuanced understanding of the dimensions of disability and the range of services and resources required to address their own needs and the needs of their children with disabilities. They also have a sense of the influence of institutional structures and arrangements on their daily experiences of caring for a disabled child. The approach that these women adopt in relation to their children’s condition is aligned with the social model of disability. They see their children’s
disability along a continuum of differences and critically assess the contextual factors that promote negative attitudes toward disability and the inclusion of those with disabilities into society. At the same time these mothers exhibit their agency within the given social structure accessing information, collaborating with professionals and creating everyday experiences that include their children in the social fabric.

The cosmopolitan mothers display a version of Merton’s (1968) ritualistic adaptation type. In Merton’s model the ritualist uses social mobility to satisfy aspirations while continuing to perform within institutional norms and boundaries. The cosmopolitan mothers function within the structurally available arrangements though their scope of social capital and understanding of cultural expectations that allows them to have greater success in attaining resources in the care of their children. These mothers occupy a social location that provides access to a variety of institutional sectors and material resources and at the same time confers social approval in their role of the “good mother.”

Interview Responses and Typology Categories

The interview portion of this study was organized to gather information relating to family structure, women’s experiences of motherhood, the process of and response to identification of the child’s diagnosis, mothers’ vision for their children and the resources needed to realize their hopes for their children. The interview also revealed expressions or indications of maternal agency within Cuba’s institutional structures. The themes elicited during the interview process add another layer of understanding to the similarities
and differences within the interview sample and the location of mothers in typology categories.

The majority of women in each typology category identified their children’s condition and then sought the necessary services. The overwhelming majority of women in each “cultural” category reported feeling emotional distress when they learned about their child’s diagnosis. When the interviewees were asked what advice they would give to another woman who has a child with disability, most women across typology groups responded that they would advise other mothers to luchar, persevere, to fight for their child. Most of the community and provincial mothers viewed their motherhood experiences as the same as women who parent typically developing children. These mothers also minimized their children’s disability when explaining it to others. This response was less frequent among cosmopolitan mothers who were more likely to explain their children’s conditions by using the terms the doctor furnished during the diagnosis process. Variations in interview responses are generally reflective of mothers’ location within the typology categories.

Most of the provincial mothers understand their children’s conditions as a medical problem. At the time of the interview the provincial mothers were more likely than either community or cosmopolitan mothers to perceive their children as normal. Fifty percent of provincial mothers envision their children developing physical skills, particularly walking. These mothers are most likely to identify “doing the exercises” as what they can do to promote their vision for their children.
Most community mothers reported feeling better about their children’s conditions at the time of the interview than they did at diagnosis. They accept the disability and feel no need to explain it. Community mothers desire their children to attend school and gain skills. When asked what resources are needed to meet their vision for their children these mothers are the most likely to indicate that they do not need anything. Community mothers offer doing the exercises, being a good mother and obtaining resources as activities they can do to help their children progress.

Half of the cosmopolitan mothers understand their children’s disability as a mistake during the birth process. These mothers are the more likely to still report having emotional distress around their children’s disabilities and to view their motherhood experiences as different than those of women with “normal” children. Cosmopolitan mothers feel that they can contribute to their vision for their children by accessing resources. They are more likely to identify material resources as what is needed for their children. The cosmopolitan mothers’ vision for their children includes social integration and the reduction of stigma.

Distinctions in the ways the women in this study approach their children’s disabilities may be explained by a myriad of factors such as cultural level, individual experiences, acceptance or rejection of the dominant disability discourse or the availability of institutional supports. Maternal educational level can surely influence how mothers understand their children’s condition and explain the condition to others. Personal experiences may shape attitudes relating to the experience of motherhood, maternal responses to their children’s diagnoses and the type of advice they give to other
mothers. Mothers who see their children as normal may indeed reject the dominant medical model discourse that views disability as tragic. These mothers may seek to reclaim their sense of control and agency in an effort to diminish the assignment of stigma onto their children and families (Fisher & Goodley, 2007; Milo, 1997). Though educational level, personal experiences and social support may contribute to varying frequency of responses within typology subgroups, whether described as class or cultural level it is the location of the mothers in the social structure that determines their placement in the study typology. As parents go through the process of knowing and adapting to their disabled children, revisions of the narrative of the child hoped for during pregnancy leads to families developing new expectations, visions and future plans for the child who is (Vacca, 2006).

This chapter began with observations of Ivette and Angelina in physical therapy gym. These observations were presented to illustrate the differing ways mothers whose children receive rehabilitation services at El Centro engage in their child’s treatment, interact with the rehabilitation staff and assert their role in the care of their disabled children. Ivette is a provincial mother. Angelina is a community mother. Of the 10 mothers observed during the intervention process, four of the women were identified as provincial mothers, three women were grouped in the community mother category, one cosmopolitan mother and two out of the three mothers in the remote group were observed. Ivette and each of the other three provincial mothers observed engaged their children during the intervention session, initiated the exercises with their child as they
waited for their appointment, manually assisted the therapist, communicated their observations of their children’s response to the intervention and demonstrated camaraderie with the other mothers. In comparison to the other typology categories, the staff appeared to engage in more social banter with the provincial mothers. The staff was also more likely to affirm the provincial mothers’ dedication to their children and the treatment regime.

Although comfortable in the gym environment, the community mothers I observed, such as Angelina, did not ask the therapists questions, did not offer their observation, were more distracted during the sessions and displayed minimal attempts in engaging their children in the treatment. Compared to the provincial mothers, this group of women positioned themselves at the edge of the therapy, though angled to view the full gym, shifting their attention away from their children. Two of the community mothers left the mat several times to talk with other women. Luz, the cosmopolitan mother effectively engaged the physical therapist in working with her child. This mother asked questions and requested the therapist’s observations of her child’s progress. Luz instructed the therapist in the massage technique she administers to her child at home. The cosmopolitan mother was not distracted by side conversations and remained focused on her child and the therapist throughout the session. She was observed to minimally socialize with the other mothers and left the gym very soon after the session ended.

As for the remote mothers, one mother placed her infant son on the mat and then left the gym for over an hour. The other mother in this category, Jennifer, was fully engaged in the treatment session, comforted her son when he cried, and initiated casual
conversation. She did not ask questions, yet she communicated her observations to the therapist. This mother had just returned to El Centro with her son after a three year absence.

The observations gathered during treatment sessions in El Centro’s physical therapy gym coupled with survey and interview findings support the value of a cultural typology in understanding differences in how mothers in Cardenas, Cuba understand their children’s disabling conditions, access services and resources, interact with professional staff and institutions and envision the future for their children. This typology is also helpful in elucidating the factors that contribute to the form and expression of agency the women in this study adopt in meeting their needs and the needs of their children. It is through the window of the rehabilitation gym of El Centro de Rehabilitacion y Neurodesarrollo that structure, culture, institutional arrangements in concert with each mother’s situated reality come together to shape the lived experience of caring for a child with disability in Cardenas, Cuba.
CHAPTER 8
CONCLUSION: OUTSIDE PERSPECTIVES AND INSIDE EXPERIENCES

“We are all Cubans.” “Socialism or death.” “We are in solidarity with people with disabilities.” “Socialism is humanism.” These statements underscore Cuba’s cultural values. We are all Cubans communicates the nation’s colorblind approach to race. The conversion of the slogan socialism or death to socialism is humanism conveys a softening of the state’s image as it reached out to the international community through its export of medical knowledge and staff. Solidarity with individuals with disability emphasizes the collective’s humanism and paternalistic care toward those in need of physical assistance. These statements also bring up questions surrounding outside perspectives of Cuba’s structure and institutions and the inside reality of daily life. The experiences and realities of women who mother children with disabilities provide a window to view how structural conceptions and institutional mechanisms come together to shape everyday life, cultural values, individual roles and behaviors. This study provides a snapshot—a moment in time—of a specific and particular group of women whose children receive rehabilitation services at El Centro de Rehabilitacion y Neurodesarrollo in Cardenas, Cuba. Yet, this study is also informed by my previous experiences in Cuba over the course of ten years. My personal and professional interests in the cultural aspects of disability led me to Cuba. I chose Cuba as it provided a stark contrast to western ideals of health, social and
economic structures and practices. As my relationship with El Centro developed I began to get an initial sense of the cultural values toward disability at El Centro and the important role Dr. Rodriguez and the mothers who brought their children to therapy had in advancing disability services at the local community level. It was then that my focus broadened to include the voices and experiences of caregivers in elucidating how social structures and institutional norms influence mothers’ attitudes and behaviors in their care of their children with disabilities.

Cuba’s model of health care and the Special Period are essential to Cuba’s narrative and particularly relevant to this study. The historical, cultural and procedural complexity of this study required exploration of a number of theoretical frameworks; undivided attention to cultural norms, boundaries and practices; balancing my role as an outsider with my efforts to look inside; framing observations and recommendations that may be viewed as critical of existing organizations and systems, while honoring the work, dedication and generosity of Dr. Rodriguez, his staff, the mothers and their children, the Cuban government and people overall. Cuba’s historic revolution set the stage for new ways to think about and approach health, education and economic development. Due to the nation’s success in extending life expectancy and controlling infectious disease Cuba is now confronted with reconfiguring it health care model to accommodate and address the needs of individuals with chronic illness and disabilities and their caregivers.

**History, The Special Period and Health Care**
The Cuban Revolution provided its citizens with free and universal access to health care. Distributive equality is a guiding principle of Cuba’s social structure. Since the time of its revolution in 1959, Cuba has been challenged by an assortment of aggressive and legislative activities initiated by the United States to topple the state’s legitimacy and socialist government. Cuba has stood strong in its resistance to American efforts to promote democracy in this island nation. The loss of financial support from the former Soviet Union in 1989 presented another and perhaps more momentous challenge to Cuba, the resulting Special Period in Time of Peace. Severe shortages of food, loss of jobs, incapacity to support state-run utilities marked by extensive and frequent electrical blackouts, limited transportation and an increase in the incidence of infectious and disabling diseases jeopardized the state’s legitimacy. The state responded to this crisis by initiating a US based dual dollar economy, permitting a handful of private businesses and identifying tourism as the foundation of its economic recovery plan. Cuba began to integrate capitalist practices into its socialist structure.

The introduction of Cuba’s dual dollar economy and focus on tourism were early contributors to economic stratification within the socialist structure. As a consequence emerging tensions between socialist ideology and material conditions along with integration of socialist and capitalist practices began to question or perhaps diminish the potency of the symbolism and message of the Cuban Revolution. Lack of material resources had a large impact on the daily lives of Cuba’s citizens during the Special Period. At the time of this study, material conditions continued to strongly influence the
daily lives of all citizens, especially mothers attempting to get medical resources for their children with special needs.

The Special Period also revealed considerable gaps in Cuba’s social sector. Individuals with disabilities were officially acknowledged by the state as a group that required attention and development of services. The dominant structural conception of disability prior to and during the Special Period could best be described as a medical hegemonic approach that located individuals on the fringe of society, mostly outside of economic, educational, health and social sectors. Individuals with disabilities were clearly taken care of, though from a paternalistic position of charity. The National Disability Priority Survey was an outcome of Special Period and set the stage for the integration and development of rehabilitation services in Cuba.

Cuba’s model health care system is internationally recognized and the premiere accomplishment of the Cuban revolution. During Cuba’ Post Special Period the export of its community based model of health care and its physicians assumed a prominent position in the nation’s economic structure and provided the state with valued symbolic capital. While Cuba was extending its reach in foreign affairs through it’s medical diplomacy program it also addressed internal health care needs. Cuba began to decentralize medical services shifting some procedures, including rehabilitation, from municipal hospitals to polyclinics. At the same time Cuba’s focus on its medical diplomacy program drew doctors away from their family clinics and perhaps postponed rigorous development of new models of health care delivery required to meet the needs of individuals with chronic illness and disability.
El Centro de Rehabilitacion y Neurodesarrollo is one of the few children’s rehabilitation centers in Cuba. Families whose children require rehabilitation services in Cardenas and throughout the province of Matanzas are often referred to El Centro for services. Regional and national referral mechanisms are underdeveloped. Although on occasion the physicians at El Centro refer families to hospitals in Havana for consultation. Infrequent and costly transportation along with limited communication options pose a burden on the families and compromise collaborative care. Families sometimes receive competing opinions and recommendations from specialists and sparse technological resources make resolution of these differences difficult. Cuba’s family doctor health care model has produced a generation of health savvy users of the system; however, access to other forms of knowledge such as the Internet and advocacy groups hinder dissemination of health information outside of primary health care.

The mothers who attend El Centro with their children generally report that they feel comfortable asking the staff questions, that the staff respects their opinions, that the staff helps them to understand their children’s conditions and that they are included in their children’s therapy sessions. These women would like El Centro to offer more rehabilitation services for their children and support services for mothers. Transportation, classes for parents and equipment for the children are reported as the services most needed in the care of their disabled children. My observations of therapy sessions emphasized the caring relationships the therapist and staff had with the mothers and their children. The environment of El Centro is warm, inviting and as stated by many of the
women interviewed “it is like family.” Yet families often wait a considerable amount of
time for their appointment and transportation.

The women who mother their children with disabilities in this study have
extensive interactions with the health care system. Due to ongoing economic constraints,
new forms of institutional arrangements, particularly in the health sector, continued to
evolve during the current Post Special Period and have led to a growing informal
economy. Many of the mothers in this study accessed the medication and equipment
needed for their children with disabilities through the informal economy. Health care
professionals often guided or assisted the mothers in their pursuit. A number of women
discussed their experiences with the other elements of the social system, especially
nongovernmental organizations, including the Federation of Cuban Women and their
local Committee for the Defense of the Revolution. Their interactions with these
organizations were very limited, often having only one contact with a representative of
the organization. Women have the primary responsibility to negotiate these new
institutional arrangements.

Disability, Motherhood and Caring for Children with Disabilities

Particular aspects of Cuba’s culture make Cuba’s social structure and in turn
conceptions of disability distinct. Cultural notions of solidarity, collectivity and
paternalism come together to form an attitude of charity and moral responsibility toward
those with disabilities. Indeed these values promote benevolence toward those with
special needs though the attitudes of charity and morality have the potential to obscure
structural, institutional and material limitations in meeting the needs of the disabled and their caregivers. Cuba conceives disability as a medical problem, a physical impairment to be remediated or prevented. Albeit, alternative perspectives such as the social model of disability are emerging at local levels. The medical model of disability promotes the expert opinion of physicians and requests that caregivers attend to the rehabilitation regime by following prescribed exercises. Within the context of this study, the caregivers are exclusively the mothers who bring their children to El Centro for rehabilitation services. The mothers’ roles as caregivers intersect with their general ideas of motherhood and their experiences within their distinct sociocultural location.

Mothering practices are contextually driven. Cuba’s Family Code defines family as the mother and child and promulgates gender equality. The cultural script of the “good mother” occupies a prominent position in Cuba. The Cuban good mother embodies cultural values of solidarity, dedication to revolutionary principles and devotion to her children. She subordinates her own interests to those of her child and the collective. Though the Cuban Family Code calls for gender equality, the cultural expectation that women perform a traditional maternal role reveals contradictions between ideology and subjective experience. Many of the women interviewed in this study adapted aspects of the good mother script to their mothering of their children with disabilities even as they acknowledged the prevailing ideological position of equality.

The Special Period had a significant impact on mothering practices in Cuba. The economic crisis led to increased single female heads of household and also resulted in a decrease in marriages as couples chose to engage in consensual unions. Compared to men
women were twice as likely to be unemployed during the Special Period. Women took on additional responsibilities and defined their own roles as *la busqueda*, to attain the resources needed for their children. Mothers who cared for their children with disabilities during the Special Period continue to face challenges in procuring resources for their children as they are often required to go beyond typical institutional patterns to access services. Caring for a disabled child reinforces gendered expectations of mothers as nurturing and intuitive, thus dismissing the need for institutional support in the care of their children.

**The Voices of Mothers: Caring for Children with Disabilities in Cardenas, Cuba**

The interview group of 34 women who care for their children with disabilities in Cardenas reported experiences that went beyond local cultural understandings and institutional mechanisms. A portion of the study findings derived from surveys, observations and interviews cut across cultural contexts. Variations within the interview group pointed to the diversity of perspectives, behaviors and roles women took on in the care of their disabled children. Other experiences reported by the interview sample are particular to Cuba’s specific sociocultural and political context.

Household arrangements and the methods mothers employ in accessing resources and information are particular to Cuba. Nearly all mothers in this study gave an account of their household as including extended family members; privileging matrifocal arrangements and receiving family help with the care of their disabled children. Structural elements of housing supply and distribution, in addition to economic constraints, are seen as the primary drivers of Cuba’s multigenerational households. Mothers go about acquiring resources in a variety ways including person-to-person
connections, accessing the informal economy or sending requests to relatives living in the United States. Strained material conditions enable and promote the informal economy as the chief mechanism to obtain needed health and medical resources. More often than not the majority of women access information relating to their children’s only through the physician. Some mothers reported that the doctor was the one to help them to come to terms with their children’s conditions.

Cuba’s model health care system grounded in the community based family doctor program is omnipresent. Physicians are involved in all aspects of their patients’ lives. The family doctor is anointed as a cultural authority and de facto representative of the state. The significant role and symbolism of health care system and its workers and its impact on everyday life is particular to Cuba. Furthermore the visibility and authority of the health care system in everyday life reinforces conceptions of disability from a strict medial perspective.

Literature originated from outside of Cuba suggest that mothers in this study share experiences and challenges in their care of their disabled children common to women in other cultural contexts. The mothers in this study expressed their joys of motherhood and the love they received from their children. Similar to women situated in other cultural locations the interview sample conveyed emotional distress when their children were diagnosed with a disabling condition, were challenged by issues of time, lack of social support and parent-professional relationships. Mothers reconstructed their narrative to replace the child they had hoped for, struggled with their children’s personhood and often displaced their own self-interests.

Within group variations underscore the diversity of the interview sample and reveals the range of differing behaviors and roles women adapt within the social structure. Interviewees varied in how they understood their children’s conditions, how
they explained their children’s disability to others, their visions, attitudes toward service provision and disability, how they acquired resources, their interactions with professional staff, and their role in promoting their children’s progress. Variations within the group of mothers led to the formation of a cultural typology based on the different roles and behaviors mothers exhibit in the care of their children with disabilities. Mothers were placed into four categories, “provincial mothers,” “community mothers,” “cosmopolitan mothers” and “remote mothers.” Due to the small sample of remote mothers and their limited engagement and response to interview and survey questions remote mothers were not included in the full analysis of the cultural typologies.

After the interview sample was placed within relevant typology categories I explored if there were any relationships between individual “cultural level” and typology location. The term cultural level was used in the context of this study to effectively describe class. An individual’s “culture level” is based on educational attainment, marital status, and economic location within Cuban society. Women categorized as provincial mothers are more likely to live in Cardenas and work outside of the home. The majority of provincial mothers are married, and this group is the least likely to have a university degree. Provincial mothers view their children’s condition as a medical problem. Their vision for their children revolves around their child’s acquisition of skills, particularly walking. The provincial mothers rely on the rehabilitation center and the expert opinion of the staff to meet their needs. The provincial mothers are the most likely to apply the cultural script of the good mother to the rehabilitation context.

Community mothers are the least likely to report being married, more likely to have attended a pre-university and about one third of the mothers work outside of the home. The mothers in this category accept their child’s condition without explanation. The community mothers are more critical of the type of services El Centro offers and are
not comfortable asking the staff questions. The community mother envisions her child going to school and often reports that she does not need anything to achieve her vision for her child.

The women identified as cosmopolitan are the most likely to have a university degree, live in Matanzas, understand their children’s condition as a mistake during birth and do not work outside of the home. Cosmopolitan women tend to be more discriminating in their views relating to cultural attitudes toward disability, access to information and their roles in their children’s progress. The type of agency women exhibit in the care of their sons and daughters with disabilities also differs in accordance with the cultural typology categories.

Agency and Context

Agency is localized. Institutional norms and material resources limit or support opportunities for enactment of collective and individual agency. Social structures establish parameters for allowable behaviors within specific situations. Types and patterns of agency are the product of both the individual’s position within the social structure and the structure’s repository of permissible and available agency. Under certain historical conditions such as Cuba’s Special Period structural boundaries are relaxed to permit alternative modes of interaction with institutional systems. This study found that the Special Period provided the women in this study with more opportunities to enact individual agency and that the type of agency that the women exhibited was related to their situated location in the cultural typology. Cosmopolitan mothers
effectively used their social capital to acquire information and material resources needed in the care of their children within institutional boundaries. The cosmopolitan mother employs her agency pragmatically. Provincial mothers gained access to services and resources through their allegiance to cultural values and commitment to structural principles while operating within institutional borders. Thus utilizing a form of structurally reproductive agency. The community mothers tended to function outside of institutional systems, value social interactions to acquire resources and seemed to be less attached to societal core values. The behaviors that these women adapted in response to limitations in material resources have the potential through their agency to transform institutional arrangements.

This study has shown that mothers of children with disabilities in Cardenas, Cuba make sense of their children’s condition mostly from a medicalized perspective of disability. Although differing perspectives are noted in this study, many of the mothers’ understandings of their children’s condition reflect the dominant view of disability as a medical problem to be eradicated or remediated. This perspective is reinforced by the lack of technological resources and integrative contexts in which to raise a child with disability. Limited accessibility to alternative sources of health information, social support and collective experiences surrounding disability results in the disjuncture between mothers’ understanding of their children’s condition and the reality of their children’s prognosis. The actions most mothers take in promoting their children’s progress and inclusion is to faithfully bring their children to therapy, follow the rehabilitation staff’s recommendations and access resources needed in the care of their
children. Approximately one-third of the 100 women who were surveyed in this study felt that they could change attitudes toward disability. Nevertheless, close to 70% of mothers reported that they could make a difference in their child’s progress, suggesting that their agency is localized and focused on their child getting better.

This study has also demonstrated that “cultural level” or class influences how mothers envision their children’s future, negotiate institutional systems and adapt their behaviors within their specific situated reality. Moreover women’s cultural level was shown to contribute to patterns of interaction with El Centro staff and how the mothers engaged in the rehabilitation process.

The voices of the mothers who participated in this study are essential in informing the development of rehabilitation services that support the mothers’ role in caring for their children with disabilities and promoting social inclusion of their children. Mothers indicated through the study survey and interviews, the vital need for transportation services, help in the home, parent-education classes, education for children about disability and counseling for mothers. This study provides a beginning understanding of the lived experiences of mothers caring for their children with disabilities in Cardenas, Cuba. The research findings and the voices of the mothers who participated in this study have the potential to assist the development of rehabilitation services at El Centro de Rehabilitacion y Neurodesarrollo. Dr. Rodriguez, the director of El Centro has begun to integrate the social model of disability that counters the dominant medical model into his practice. The social model of disability considers contextual factors that limit the inclusion and participation of individuals with disabilities in society. Extension of the
social model to educational environments and the community would further support inclusion of children with disabilities within their local school and lend a hand to changing attitudes toward disability.

Assessment of social support services and systems would be beneficial in determining programs and resources available to mothers and their children with disabilities. Assignment of social workers to families, establishment of referral mechanisms between institutions, and collaboration/coordination with the Federation of Cuban Women and other nongovernmental organizations are instrumental to providing support to mothers. Parent support groups and additional avenues to access and distribute information are essential to mothers’ understandings of disability. Training of paraprofessional health care aides would address the mothers request for skilled help at home. These suggestions need to be considered within the context of Cuba’s cultural, political and economic environments.

Cuba is ever changing. I have had the privilege to witness the grassroots efforts of a local pediatric neurologist in transforming notions of disability within his community. The direction of this change is not top down but rather originating from the everyday lived experiences of mothers of children with disability and their health care providers. It will be important to observe Dr. Rodriguez’s on-going grassroots, bottom up approach to see if it has the potential to influence structural conceptions and institutional arrangements of disability. The voices of the women who mother their children with disabilities will offer an important perspective in informing the advancement of disability services in Cuba.
BIBLIOGRAPHY


264


*Por La Vida, Estudio de las personas con retraso mental y otra discapacidades* [video]. (2004). República de Cuba.


## APPENDICES

### APPENDIX A

### TIMELINE OF US–CUBA RELATIONS

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>January 1, 1959</td>
<td>Last battle in the revolution against Fulgencio Batista. Batista flees to the Dominican Republic. Fidel Castro assumes power</td>
</tr>
<tr>
<td>October 1960</td>
<td>US imposes economic embargo prohibiting exports to Cuba with the exception of food, medicine and medical supplies</td>
</tr>
<tr>
<td>January 1961</td>
<td>US closes its embassy in Havana, breaks off diplomatic relations with Cuba</td>
</tr>
<tr>
<td>April 1961</td>
<td>US supported Cuban exiles invade the Bay of Pigs</td>
</tr>
<tr>
<td>January 1962</td>
<td>Cuba suspended from the Organization of American States</td>
</tr>
<tr>
<td>February 1962</td>
<td>US government bans all imports from Cuba and cuts off aid to any country that provides assistance to Cuba</td>
</tr>
<tr>
<td>October 1962</td>
<td>US tightens the Embargo, closing ports to nations that allow ships to carry arms to Cuba</td>
</tr>
<tr>
<td>October 1962</td>
<td>Cuban Missile Crisis</td>
</tr>
<tr>
<td>July 1963</td>
<td>Embargo tightened, most travel to Cuba for US citizens is illegal</td>
</tr>
<tr>
<td>March 1977</td>
<td>US lifts prohibition on travel for three months then reinstates it, Cuba and US agree to open Interests Sections in each other’s capitals</td>
</tr>
<tr>
<td>April 1980</td>
<td>Mariel Boat Lift</td>
</tr>
<tr>
<td>October 1992</td>
<td>Congress passes the Cuban Democracy Act prohibiting foreign based subsidiaries of US companies trading with Cuba</td>
</tr>
<tr>
<td>March 1996</td>
<td>The Cuban Liberty and Democratic Solidarity Act is passed</td>
</tr>
<tr>
<td>February 1997</td>
<td>Clinton Administration approves licenses for US new organizations to open up offices in Cuba</td>
</tr>
<tr>
<td>November 1999</td>
<td>Elian Gonzalez found in the Straits of Florida on Thanksgiving Day</td>
</tr>
<tr>
<td>June 2003</td>
<td>President George Bush establishes the Committee for Assistance to Free Cuba, eliminates academic and cultural trips to Cuba</td>
</tr>
<tr>
<td>July 2006</td>
<td>Transfer of presidential power from Fidel Castro to his brother Raul Castro</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1959</td>
<td>Cuban Revolution</td>
</tr>
<tr>
<td>1982</td>
<td>Formation of the Action for People with Disability provided universal medical access, created rehabilitation programs and special education schools</td>
</tr>
<tr>
<td>1982-1992</td>
<td>Accelerated genetic testing to prevent the incidence of disability</td>
</tr>
<tr>
<td>1992</td>
<td>Association for the Blind, Cuban Association for the Deaf and Cuban Association for Individuals with Limited Motor Function established as non-governmental organizations</td>
</tr>
<tr>
<td>1992-2002</td>
<td>Minimal growth in rehabilitation services due to economic crisis, expansion of Julio Diaz Rehabilitation Center, First Rehabilitation Scientific Congress</td>
</tr>
<tr>
<td>2002</td>
<td>First National Disability Study</td>
</tr>
<tr>
<td></td>
<td>El Centro de Rehabilitacion y Neurodesarrollo established in Cardenas, Cuba</td>
</tr>
<tr>
<td>2003</td>
<td>First census of individuals with disabilities</td>
</tr>
<tr>
<td>2005-2006</td>
<td>Expansion of rehabilitation services to polyclinics</td>
</tr>
</tbody>
</table>
APPENDIX C
INTerview Guide

Site: _______________________

Date: _______________________

Study Identification Number: __________

Start Time: _______________________

End Time: _______________________

Introduction

Thank you for taking the time to speak with me. I am Debra Tupé, an assistant professor of clinical occupational therapy at Columbia University in New York and a graduate student at Temple University in Philadelphia, Pennsylvania in the United States of America. I have been working with Dr. Jorge Rodriguez at El Centro de Rehabilitacion over the past 5 years. Today I would like to talk to you about your experiences as a mother of a child with disability. Our interview is confidential and your identity will not be shared with anyone. Participating in this interview may involve recalling experiences that may cause you to feel uncomfortable. You may refuse to answer any question.
without providing an explanation for your refusal. You may interrupt or end the interview at any time.

Do I have your consent to participate in this interview?  Yes  No

May I have your consent to tape the interview so that I can more accurately document your responses for the investigation?  Yes  No

Do you have any questions before we begin?  Yes  No
Interview Script

To begin with I would like to know about you and your family.

Tell me about your experiences as a mother.

Now I would like to know a little more about your child with disability. Tell me how you learned about your child’s disability.

How did you make sense of your child’s disability when you first learned of your child’s condition? Do you still think of your child’s disability the same way now?

Are your experiences as a mother different with a child with disability?
How do your family and friends understand your child’s disability? How do you explain your child’s disability to them?

What advice would you give to a friend about disability?

What is your dream for your child and family?

What do you need to make that dream happen?
APPENDIX D
QUESTIONNAIRE

Respondent ID: __________________

Date: __________________

SELF ADMINISTERED QUESTIONNAIRE
MOTHERS OF CHILDREN WITH DISABILITY RECEIVING SERVICES AT
EL CENTRO DE REHABILITACION DEL NEURODESARROLLO
CARDENAS, CUBA

I. Introduction

Thank you for agreeing to participate in this questionnaire. The purpose of this questionnaire is to collect information that will be used to understand the concerns and needs of families whose children receive services at El Centro de Rehabilitacion del Neurodesarrollo in Cardenas, Cuba in an effort to improve care children and families receive at the center. This questionnaire should take about 20 minutes to complete. The questionnaire information is confidential and your identity will not be shared with anyone. Participating in this questionnaire will request reporting of feelings or experiences that may cause you to feel uncomfortable. You may refuse to respond to any
question without providing an explanation for your refusal and you may terminate completion of the questionnaire at any time.

Do I have your consent to participate in this questionnaire?______________
II. Background Information

Please write your response to each of the following questions

B1. What is the date of your birth?
   Day___________
   Month_______
   Year__________

B2. Where were you born? _______________________

B3. Where do you live now? _____________________

B4. How long have you been where you live now? ____________

B5. How many children do you have?
   ________________

B6. Please list the gender and age of each of your children.
   Gender       Age

   _______      _______
B7. Please identify the gender and age of your child (ren) who receives services at El Centro de Rehabilitacion del Neurodesarrollo?

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

B8. Please identify the type of services your child (ren) receives at El Centro de Rehabilitacion del Neurodesarrollo? Please place a check mark next to each service that your child or you receive.

- [ ] medical care
- [ ] physical therapy
- [ ] speech therapy
- [ ] occupational therapy
- [ ] dental care
- [ ] music therapy
______ psychology  ______ art therapy
______ dance therapy  ______ visual therapy
______ education  ______ counseling
______ feeding therapy  ______ parent support group

B9. Please tell me why your child receives these services?

_____________________________________________________________________

B10. Has your child been identified as having a particular medical diagnosis or condition? [CIRCLE ONE]

A. Yes       B. No

If you answered yes, please identify your child’s diagnosis or condition.

_____________________________________________________________________

B11. Does your child attend school? [CIRCLE ONE]

A. Yes       B. No

If you answered yes, please identify the school your child attends.

_____________________________________________________________________

279
If you answered no, please tell me why your child does not go to school

__________________________________________________________________

B12. Does your child regularly play with other children? [CIRCLE ONE]

A. Yes       B. No

If you answered yes, please place a check next to whom your child usually plays with

__________ brother  __________ classmate
__________ sister  __________ neighborhood friend
__________ cousin

If you answered no, please tell me why your child usually does not play with other children?

__________________________________________________________________

B13. What is your marital status? [CIRCLE ONE]

A. Single never married
B. Married

C. Divorced

D. Widowed

E. Other [SPECIFY]: ________________________

B14. What is the last level of school you completed? [CIRCLE ONE]

A. Grade school

B. High school

C. College

D. Graduate or professional school

B15. Do you work outside of your home?[CIRCLE ONE]

A. Yes  B. No

If you answered yes, what type of work do you do?

______________________________
**B16.** Who in your household is primarily responsible for homemaking activities including cooking, cleaning, other household chores? _____________________

**B17.** Who in your household is primarily responsible for taking care of your child with special needs? ________________________________

**B18.** Do any family members or friends assist with the care of your child with special needs? [CIRCLE ONE]

A. Yes  B. No

**B19.** If you responded yes to the previous question please place a check mark next to the person who helps you the most with care of your child with special needs.

________ husband  __________ child’s grandfather
________ boyfriend  __________ child’s aunt
________ child’s grandmother  __________ child’s uncle
________ child’s sibling  __________ friend
B. 20. Please place a check mark next to each of the following that you think would be helpful in supporting children with disabilities and their families

- transportation
- classes for parents
- more household help
- more therapy
- availability of school
- education for mothers
- counseling for mothers
- counseling for siblings
- equipment for child
- teaching children about disability
- changing attitudes

III. Rehabilitation Services

Please read each of the following statements and circle the response that best expresses your feelings about the statement

1. The Center offers all of the rehabilitation services my child needs

   [CIRCLE ONE]

   1. No  2. Yes, most of the services  3. Yes, all of the services

2. The Center provides the support services that I need to help my child

   [CIRCLE ONE]

   1. No  2. Yes, most of the services  3. Yes, all of the services
3. The staff at the Center helps me to understand my child’s condition

[CIRCLE ONE]

1. No  2. Yes, most of the time  3. Yes, all of the time

4. I feel comfortable asking the staff questions about my child’s condition and therapy

[CIRCLE ONE]

1. No  2. Yes, most of the time  3. Yes, all of the time

5. The staff includes me in my child’s therapy program [CIRCLE ONE]

1. No  2. Yes, most of the time  3. Yes, all of the time

6. The Center provides adequate educational activities for parents [CIRCLE ONE]

1. No  2. Yes, most of the time  3. Yes, all of the time

7. I believe that I can make a difference in my child’s progress [CIRCLE ONE]

1. No  2. Yes, most of the time  3. Yes, all of the time

8. The staff respects my opinions [CIRCLE ONE]
9. I feel that people in my community have a positive attitude toward my child with special needs or disability [CIRCLE ONE]

1. No  
2. Yes, most of the time  
3. Yes, all of the time

10. I believe that I can make a difference in other peoples’ attitudes toward my child with special needs or disability [CIRCLE ONE]

1. No.  
2. Yes, most of the time  
3. Yes, all of the time

Thank you for your time and responses.

Please offer any comments, concerns or questions that you may have below.
APPENDIX E
GUÍA PARA LAS ENTREVISTAS

Lugar: _______________________

Fecha: _______________________

Número de identificación del Estudio: _________

Hora al comienzo: ____________________________

Hora al final: _______________________________

Introducción

Gracias por tomarse en tiempo para hablar conmigo. Soy Debra Tupé, Profesora Asistente de Terapia Ocupacional en la Universidad de Columbia, en Nueva York, y estudiante de estudios graduados en la Universidad de Temple en Filadelfía, Pennsylvania, en los Estados Unidos de América. Durante los últimos 5 años he estado trabajando con el Dr. Jorge Rodríguez en el Centro de Rehabilitación. Hoy quisiera hablarles acerca de sus experiencias como madre de un niño/a discapacitado. La información en nuestra entrevista será confidencial, y su identidad no será divulgada o
compartida con nadie. Puede que al participar en esta entrevista tenga que recordar experiencias desagradables que la hagan sentirse incómoda. Puede negarse a contestar cualquiera de las preguntas sin necesidad de explicar la razón por la cual prefiere no contestarla. Y, desde luego, puede interrumpir, o terminar, la entrevista en cualquier momento que lo estime necesario.

¿Me da su consentimiento para participar en esta entrevista?    Sí            No

¿Me da su consentimiento para grabar la entrevista y así poder documentar más fielmente sus respuestas en el estudio?    Sí            No

¿Tiene alguna pregunta antes de comenzar?    Sí            No
Diálogo de la Entrevista

Para empezar me gustaría saber algo acerca de usted y su familia.

Hábleme de su experiencia como madre.

Ahora me gustaría saber un poco más acerca de su niño/a que está discapacitado/a.

Dígame como fue que se dio cuenta de la discapacidad de su niño/a.

¿Qué pensó de la condición de su niño/a la primera vez que su discapacidad fue diagnosticada? ¿Piensa lo mismo hoy en día?
¿Son sus experiencias como madre diferentes con respecto a su niño/a
discapacitado?

¿Cómo entienden sus amigos y familiares la discapacidad de su niño/a? ¿Cómo
se la explica a ellos?

¿Qué consejo le daría a una amiga acerca de la discapacidad?

¿Cuál es su sueño para su niño/a y para su familia?

¿Qué necesita para realizar ese sueño??
APPENDIX F
CUESTIONARIO

Sujeto ID:________________

Fecha:________________

PREGUNTAS A CONTESTAR POR SI MISMA
MADRES DE NIÑOS/AS DISCAPACITADOS RECIBIENDO ATENCIÓN EN
EL CENTRO DE REHABILITACIÓN DEL NEURODESARROLLO
CÁRDENAS, CUBA

I. Introducción

Gracias por acceder a participar en este cuestionario. El propósito del mismo es el de obtener información que pueda usarse para entender mejor las preocupaciones y necesidades de las familias cuyos niños reciben los servicios del Centro de Rehabilitación del Neurodesarrollo in Cárdenas, Cuba, en un esfuerzo para mejorar el cuidado que los niños y sus familias reciben en el Centro. Completar este cuestionario debe tomar unos 20 minutos. La información en el mismo es confidencial y su identidad no será revelada a nadie. Ciertas preguntas piden información acerca de sentimientos o experiencias que podrían producirle algún desasosiego. Puede negarse a responder a cualquier pregunta sin necesidad de explicación, y puede dar por terminado el cuestionario en cualquier momento.

¿Me da su consentimiento para participar en este cuestionario?______________
II. Antecedentes

Por favor, indique por escrito su respuesta a las siguientes preguntas.

B1. Fecha de nacimiento

Día___________
Mes_________
Año__________

B2. ¿Dónde nació? _______________________

B3. ¿Dónde vive ahora? _____________________

B4. ¿Por cuanto tiempo ha residido donde vive ahora? ____________

B5. ¿Cuántos niños tiene?

_________________

B6. Por favor, indique el sexo y la edad de cada uno de los niños.

<table>
<thead>
<tr>
<th>Sexo</th>
<th>Edad</th>
</tr>
</thead>
<tbody>
<tr>
<td>________</td>
<td>________</td>
</tr>
</tbody>
</table>
B7. Por favor, indique el sexo y la edad de cada uno de sus niños/as que recibe atención en el Centro de Rehabilitación del Neurodesarrollo?

<table>
<thead>
<tr>
<th>Sexo</th>
<th>Edad</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>

B8. Por favor, identifique los tipos de servicios que sus niños/as reciben en el Centro de Rehabilitación del Neurodesarrollo. Marque cada servicio que están recibiendo.

- ______ cuidado médico
- ______ terapia física
- ______ terapia de lenguaje
- ______ terapia ocupacional
- ______ cuidado dental
- ______ terapia musical
- ______ psicoterapia
- ______ terapia de arte
________terapia de danza                            _______terapia visual
________educación                                     ________consejería
________terapia de alimentación                 ________grupo de apoyo para padres

**B9.** Por favor, indique la razón por la cual su niño/a recibe esos servicios.
__________________________________________________________________

**B10.** ¿Se ha identificado su niño/a como teniendo un diagnostico o condición médica en particular? [MARQUE UNO CON UN CÍRCULO]

A. Sí  B. No

Si la respuesta es sí, por favor, identifique el diagnóstico o condición de su niño/a.

**B11.** ¿Va su niño/a a la escuela?[MARQUE UNO CON UN CÍRCULO]

A. Sí  B. No

Si la respuesta en sí, por favor, identifique la escuela a la que va su niño/a.

Si la respuesta es no, por favor, indique la razón por la cual su niño/a no va a la escuela.
__________________________________________________________________

293
B12. ¿Juega su niño/a regularmente con otros niños? [MARQUE UNO CON UN CÍRCULO]

A. Sí   B. No

Si su respuesta es sí, por favor, marque con quién más frecuentemente juega su niño/a.

_________ hermano                    _________ compañero de escuela
_________ hermana                       _________ amigo del vecindario
_________ primo/a

Si su respuesta es no, por favor, indique la razón por la cual su niño/a no juega con otros niños.

B13. Estado civil [MARQUE CON UN CÍRCULO]

A. Soltera, nunca se ha casado

B. Casada

C. Divorciada

D. Viuda
E. Otro [ESPECIFIQUE]: ________________________

**B14.** ¿Cuál es el nivel de educación más alto alcanzado? [MARQUE UNO CON UN CÍRCULO]

A. Escuela primaria  
B. Escuela secundaria básica  
C. Preuniversitario  
D. Universidad  
E. Politécnicos

**B15.** ¿Trabaja fuera de la casa?[MARQUE CON UN CÍRCULO]

A. Sí  
B. No

Si la respuesta es sí, qué tipo de trabajo hace usted.?

____________________________________

**B16.** En su casa, ¿quién es principalmente responsable por los quehaceres cotidianos, como cocinar, limpiar, y otras tareas similares?

____________________________________
B17. En su casa, ¿quién es principalmente responsable por el cuidado de su niño/a con necesidades especiales?

____________________________________________

B18. ¿Miembros de la familia, o amigos/as, ayudan con el cuidado de su niño/a con necesidades especiales? [MARQUE CON UN CÍRCULO]

A. Sí    B. No

B19. Si la respuesta a la pregunta anterior es sí, ponga una marca junto a la persona que más la ayuda a cuidar a su niño/a con necesidades especiales.

________esposo                                     ________abuelo del niño/a
________compañero                                  ________tía del niño/a
________abuela del niño/a                           ________tío del niño/a
________hermano/a del niño/a                       ________amigo/a

B. 20. Por favor, marque cada uno de los siguientes servicios que usted consideraría útiles para la ayuda de niños/as discapacitados y sus familias.

________transporte                                  ________clases para padres
________más ayuda en la casa                        ________más terapia
________accesibilidad a escuelas                    ________educación para madres
III. Servicios de Rehabilitación

Por favor, lea cada una de las siguientes declaraciones y ponga un círculo alrededor de la respuesta que mejor exprese su opinión.

1. El Centro ofrece todos los servicios de rehabilitación que mi niño/a necesita. [MARQUE CON UN CÍRCULO]

   1. No
   2. Sí, la mayoría de los servicios
   3. Sí, todos los servicios

2. El Centro me proporciona los servicios de asistencia que yo necesito para ayudar a mi niño/a. [MARQUE CON UN CÍRCULO]

   1. No
   2. Sí, la mayoría de los servicios
   3. Sí, todos los servicios

3. El personal del Centro me ayuda a comprender la condición de mi niño/a. [MARQUE CON UN CÍRCULO]

   1. No
   2. Sí, la mayoría de las veces
   3. Sí, siempre

297
4. No tengo problema haciendo preguntas al personal del Centro a cerca de la terapia o la condición de mi niño/a. [MARQUE CON UN CÍRCULO]

   1. No    2. Sí, la mayoría de las veces    3. Sí, siempre

5. El personal me incluye en el programa de terapia de mi niño/a. [MARQUE CON UN CÍRCULO]

   1. No    2. Sí, la mayoría de las veces    3. Sí, siempre

6. El Centro ofrece adecuadas actividades educacionales para los padres. [MARQUE CON UN CÍRCULO]

   1. No    2. Sí, la mayoría de las veces    3. Sí, siempre

7. Creo que puedo hacer una diferencia en el progreso de mi niño/a. [MARQUE CON UN CÍRCULO]

   1. No    2. Sí, la mayoría de las veces    3. Sí, siempre

8. El personal del Centro respeta mis opiniones [MARQUE CON UN CÍRCULO]

   1. No    2. Sí, la mayoría de las veces    3. Sí, siempre
9. Siento que las personas en mi comunidad tienen una actitud positiva hacia mi niño/a discapacitado o con necesidades especiales. [MARQUE CON UN CÍRCULO]

1. No 2. Sí, la mayoría de las veces 3. Sí, siempre

10. Creo que puedo hacer una diferencia en la actitud que otras personas tienen hacia mi niño/a discapacitado o con necesidades especiales. [MARQUE CON UN CÍRCULO]

1. No 2. Sí, la mayoría de las veces 3. Sí, siempre

Gracias por su tiempo y sus respuestas.
Por favor, ofrezca cualquier comentario, preocupación, o pregunta que pueda tener. Use el espacio más abajo.
### APPENDIX G

#### OBSERVATION CODING

<table>
<thead>
<tr>
<th></th>
<th>Mother</th>
<th>Therapist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greeting upon entrance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initiates conversation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asks questions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invites other into session</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initiates entry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Engages with child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Engages with other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assists manually</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Offers suggestions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instructs other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicates observations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diverts attention to other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>event</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distracted</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detached</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides summary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Termination</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Comments:**

________________________________________________________________________

________________________________________________________________________
INTERVIEW THEMATIC CODING GUIDE

Tell me about your family
• Family composition
• Family coherence
• Family support

Tell me about your experiences as mother
• Enjoyable experiences
• Challenging experiences
• Daily routines

Tell me about your child who receives services at the center
• Begins with child’s characteristics
• Begins with child’s disability
• Describes the identification of the diagnosis

Tell me how you learned about your child’s disability/condition
• Doctor identified at birth
• Delayed doctor identification
• Mother identified and sought services
• Mother offered very detailed narrative
• Mother displays understanding of diagnosis
• Mother could not offer diagnosis
• Mother sought additional services

How did you feel when you first found out?
• Emotional distress
• Cognitive response
• Spiritual response

How do you feel about your child’s condition now?
• Feel better now
• It is still hard
• It is like my child is normal

How do you make sense/understand your child’s disability/condition?
• Medical problem
• Problem with delivery
• Accept it, don’t try to explain it

Are your experiences as a mother different with a child with disability?
• Different
• About the same
• The same

How do you explain your child’s disability/conditions to your family and friends?
• He is normal
• Minimize the condition
• I tell them what the doctor said

What advice would you give to a friend who has a child that has disability?
• To fight
• To love child
• To be a good mother and not give up
• Other

What is your dream/vision for your child?
• Social integration
• School
• Attributes
• skills

What do you need to make that dream happen?
• I don’t know, nothing
• Do the exercises
• Material resources
• other

What can you do to make that dream happen?
• Do the exercises
• Be a good mother
• Seek resources