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Educating Children with down Syndrome in Lebanon: An Exploratory Study of Urban Mothers' Perspective

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EDUCATING CHILDREN WITH DOWN SYNDROME IN LEBANON:
AN EXPLORATORY STUDY OF URBAN MOTHERS’ PERSPECTIVE

By

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In loving memory of my parents

Joseph S. Hatoum, MBE, and Claire I. Eid-Hatoum,
the best parents and role models one could hope for.
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## TABLE OF CONTENTS

List of Tables ........................................................................................................ vii
Abstract .............................................................................................................. viii

1. INTRODUCTION .......................................................................................... 1

   Statement of the Problem ............................................................................... 1
   Research Study’s Context: Lebanon ............................................................... 4
   Research Study’s Purpose, Questions, and Rationale ....................................... 24
   Need for and Significance of Study ............................................................... 32
   Summary and Transition ............................................................................... 33

2. REVIEW OF THE LITERATURE .................................................................. 34

   Introduction .................................................................................................... 34
   Impact of Disability on Families ..................................................................... 36
   Views of Disability .......................................................................................... 38
   Evolution of Parents’ Role .............................................................................. 40
   Evolution of Intervention Programs ............................................................... 43
   Cross-Cultural Perspectives ........................................................................... 44
   Methodological Limitations ........................................................................... 47
   Conclusion of Literature Review ..................................................................... 47
   Summary and Transition ............................................................................... 48

3. RESEARCH METHOD .................................................................................. 49

   Introduction .................................................................................................... 49
   Strategy of Inquiry, Paradigm, and Perspective ................................................ 50
   Method of Collecting Empirical Materials ....................................................... 50
   Researcher’s Role ............................................................................................ 51
   Researcher’s Background ............................................................................... 52
   Researcher’s Relationship with Participants ................................................... 54
   Ethical Considerations ..................................................................................... 55
   Procedure for Selecting Informants and Participants ....................................... 59
   Procedures for Collecting Empirical Materials ............................................... 65
LIST OF TABLES

Table 1: Participants’ Demographic Information .................................................. 64
Table 2: Participants’ Children with DS Demographic Information ..................... 66
Table 3: Procedures Used to Ensure the Trustworthiness of the Study’s Empirical Findings ................................................................. 81
Table 4: Participant and Informant Validation Summary ...................................... 82
In view of the fact that Lebanon does not currently have a special education infrastructure, the purpose of this exploratory qualitative study was to understand the phenomenon of educating children with Down syndrome (DS) in Lebanon in terms of the meanings mothers ascribe to it and their description of their experience. The intent was to develop a conceptual ordering of the dynamics of the process that explains their experience and to identify critical factors that surround their quest for educational and related services for their children with DS.

Empirical materials were collected through individual, face to face, semi-structured, long, qualitative interviews with 12 urban mothers of children with DS who are in the elementary school age range. Analysis of the empirical materials revealed that mothers are the vital and driving force behind securing programs for their children with DS and that they go through the following four related processes: (1) adapting to a new reality, (2) pursuing educational programs and related services, (3) accommodating to uncertainty, and (4) preserving self. In addition, four key factors in educating children with DS in Lebanon were identified: (1) financial resources, (2) mother’s background and characteristics, (3) support, and (4) religion. After discussing these empirical findings and comparing them with extant literature, recommendations for research, practice, and policy development are provided.
CHAPTER 1

INTRODUCTION

Mental retardation has been described as probably the most dreadful diagnosis a parent can receive (Fewell, 1986) and as a tragedy analogous to death (Davis, 1987; Nicholas & Lewin, 1986). The feelings of shock, disappointment, uncertainty, ambivalence, guilt, grief, and depression that parents might experience when they realize that their child has a disability have been amply documented (e.g., Blacher, 1984a, 1984b; Hodapp, 1988; Shapiro, Blacher, & Lopez, 1998). These reactions and emotional states, along with the parents’ conception of the nature of the disability and the expectations they derive from their understanding of its ramifications, could have a significant impact on the overall parenting style as well as on the type and quality of parent-child interactions (Atkinson et al., 1995), which eventually shape child behavior and development. According to Marfo, Dedrick, and Barbour (1998):

The extensive research on the emotions and stresses associated with having and rearing a child with disabilities supports the proposition that the parent’s assumptive world (i.e., the set of assumptions, perceptions, and expectations that organizes one’s emotional experiences and directs one’s behavior) directly or indirectly influences parental well-being, family integrity, parent-child interactions, and, ultimately, child behavior and development (p. 664).

Early research on the impact of the birth of children with disabilities on families (usually mothers) adopted a pathological view of maternal adjustment and presented a grim picture of stress, burden, depression, psychological dysfunction, marital discord, and social isolation (Shapiro, 1983). Later research that explored complex personal, social, and ecological variables that mediate and moderate the impact of disability on the family, emphasized the interactive and developmental nature of maternal adjustment, and situated maternal adaptation within the context of a multitude of intrapersonal and external factors (Shapiro, Blacher, & Lopez 1998). This shift in logic from the psychodynamic to the psychosocial approach to maternal adjustment to a child with a disability reflected changes in the dominant professional perspective in the western world (North America and Western Europe) where most of the research studies were conducted. Unfortunately however, until recently two key perspectives have been ignored in that literature, namely: the parents’ perspective [direct accounts by parents] (Ferguson, 2002; Singer, 2002) and the cultural perspective [contextual and cultural relativity of disability issues] (Ferguson, 2002; Harry, 2002; Singer, 2002).
Emily Perl Kingsley (1987), whose son Jason has Down syndrome described her experience as follows:

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this . . .

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guide books and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you never would have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around . . . and you begin to notice Holland has windmills . . . and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy . . . and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever go away . . . because the loss of that dream is a very, very significant loss.

But . . . if you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the very special, the very lovely things . . . about Holland.

Since she wrote it in 1987, this inspirational essay has had such resonance with parents that it has been translated into numerous languages (at least 14), quoted frequently, reprinted regularly in many forms (including in Dear Abby’s column, every October, for National Down Syndrome
Awareness Month and in *Chicken Soup for the Mother’s Soul*, published on scores of websites, set to music, worked into a patchwork quilt, and even used as the theme for disability conferences (Blitchington, 2000; Creative Parents.com, 2001; Journey of Hearts.org, 1998). This could be due to the fact that Mrs. Kingsley successfully portrayed a shared experience and evoked an outlook that parents identify with. She aptly used the travel metaphor to describe her initial disorientation, the persisting pain associated with her lost dream, her quest for information and support, her acceptance, and finally her appreciation of the dimensions of having a child with a disability. It is noteworthy, though, that an obviously privileged socio-economic and cultural context is implicit in her eloquent representation of her experience. However, regardless of her personal attributes and socio-economic status, the mere fact that she resides in the United States of America puts her at a distinct advantage over mothers of children with disabilities in most other countries. Besides the fact that the USA is one of the most affluent countries in the world, it has had a long history of providing appropriate services for people with disabilities. In fact, it has been at the forefront of asserting the rights of individuals with disabilities and of advocating for the provision of education and related services in the least restrictive environment for over 30 years (since the promulgation of the Education for the Handicapped Act [EHA], Public Law 94-142 in 1975, the precursor of the Individuals with Disabilities Education Improvement Act of 2004 [IDEA]) and has developed an arguably state of the art set of laws and regulations that mandate and fund a well-coordinated system of services and support. This infrastructure might be available—though perhaps not as well articulated—in a few other western countries, but is definitely lacking in the majority of developing countries. More often than not, in such countries, parents are essentially left to fend for themselves in uncharted territory with minimal resources—if any—when upon learning that their baby has a disability, the constellation of emotions floods their hearts, suspends their thought process, and immobilizes them with fear of the unknown. Their precarious situation might also be exacerbated by limited financial resources, as well as by—among other factors—religious, social, and cultural beliefs about disabilities.

The question is how do these parents deal with this enormous challenge? What are the critical factors that influence their behavior under those circumstances? What are the dynamics of the process they go through to obtain the educational and related services needed for their children with disabilities? These questions have not been investigated in Lebanon. In fact, there is a dearth of information about disability issues in general and there are no systematic accounts or research studies on the subject.

The intent of this qualitative study was to explore the phenomenon of educating children with Down syndrome in Lebanon, a war-torn developing country that currently lacks a special education and related services infrastructure. Before discussing the research project, in order to set the stage for the investigation, a brief overview of the socio-cultural context that permeates the lives of participants in the study and underlays the targeted problem is provided. After this overview of the context, the purpose, the research questions, the rationale, as well as the need for and the significance of the study will be presented.
The following general overview of the research study’s context highlights major aspects of Lebanon’s geography, history, population, government, economy, education, and culture in order to give the reader a feel for the atmosphere that pervades the country and impinges on people’s everyday life. This substrate was taken into consideration in designing and conducting the study. It also served as the backdrop for interpreting its empirical findings.

Lebanon is a small country on the eastern shore of the Mediterranean Sea (coastline is about 150 miles long), between Syria (north and east) and Israel (south). Its name means “milky-white” in reference to the snow that covers the country’s mountain peaks (highest altitude is 10,112 feet) for almost half the year. Its geographic location at the intersection of three continents (Europe, Asia, and Africa) confers to it a cosmopolitan character and a multicultural legacy (Malik, 2002). It also contributes to its “heterodoxical nature” (Cobban, 1985, pp. 9 & 11). Its rugged terrain and soaring mountains have historically helped isolate, provide refuge, and develop numerous factional groups based on religion, clan, and ethnicity (CIA, 2007; Cobban, 1985).

Having only 4,500 square miles of territory (Embassy of Lebanon, Washington, D. C., 2007), Lebanon is about 0.7 times the size of Connecticut (CIA, 2007) and according to Winslow (1996, p. 1), “a bit larger than Yellowstone National Park, but ‘with more lethal wildlife,’ as old hands in the diplomatic establishment used to say.” The comment is inspired undoubtedly by the long saga of atrocities, which seemed to have no purpose or end, associated with the 15-year civil war (1975-1990) that ravaged the country. According to Picard (2002):

> As events succeeded one another, reflection and analysis lost their way in the mindless and bloody turmoil. Nothing made sense or fit our understanding: the obscene reversal of alliances; the carnage between two valleys or two villages or two families; the serial assassinations of political figures; and the systematic destruction of the nation’s resources. (Picard, 2002, p. vii)

Nevertheless, no matter how senseless and idiosyncratic the internal conflicts of this small country may have appeared to be, they had reverberations far beyond Lebanon’s borders. In fact, they had sufficient impact to generate new terminology. According to Harris (1997) a new word, “Libanisation,” (Lebanonization) was formally added to the French language in 1991. It is defined in the Larousse dictionary as “processus de fragmentation d’un Etat, résultant de l’affrontement entre diverses communautés [process of fragmentation of a state, as a result of confrontation between diverse communities]” (Harris, 1997, p. 1). “Libanisation” and its English equivalent have been used since the end of the eighties to describe turmoil affecting multi-communal states after the Cold War. In 1994, a brief note was published in Lebanon’s prominent

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1 - Lebanon’s aspiration to be the Switzerland of the Middle East may have been shattered by the 1975-1990 civil war (Malik, 2002).
newspaper *An-Nahar* to express “the annoyance of senior Lebanese religious personalities that their country should be the exemplar for . . . [such] . . . turbulence” (Harris, 1997, p. 1).

Not only did the 15-year civil war destroy Lebanon’s physical appearance and infrastructure, the huge number of casualties reduced its population. In addition, thousands of Lebanese were displaced from their homes and thousands of them emigrated, resulting in a brain drain and an outflow of capital.

In the early 1990s, with the enhanced atmosphere of peace, stability, and security, Lebanon started a process of recovery and reconstruction. Rafiq Hariri, a self-made billionaire businessman, who was appointed Prime Minister in 1992, initiated many reconstruction projects to redevelop war-torn Lebanon’s physical and financial infrastructure and dominated the country's post-war political and business life. Although Hariri is widely credited with getting the country back on its feet after the devastating civil war, he is also blamed for the significant increase in the national debt, despite receipt of $2 billion in bilateral assistance at the Paris II Donors’ conference (CIA, 2007).

On May 24, 2000, yielding to the demands of the United Nations Security Council Resolution 425 and to international pressure, Israel withdrew from most of the territory it had occupied in south Lebanon for 22 years (1978-2000), which it referred to as a “security zone.” However, Israel still retains the water rich fertile area of Sheb’a Farms, to the chagrin of Hezbollah whose avowed mission is to liberate every inch of Lebanese soil.

The Israeli withdrawal was followed by a period of jubilation and further growth and prosperity. It encouraged some Lebanese groups to demand the withdrawal of Syrian forces as well. The capital, Beirut, a vibrant and stylish city, which before the civil war was considered to be the “Pearl” or the “Paris” of the Middle East (Lebanese Ministry of Tourism, 2007), was reported on March 4, 2004, to be fast reclaiming its pre-war reputation as the cultural capital of that region (Owens, 2004).

However, on February 14, 2005, the former Prime Minister, Rafiq Hariri, was assassinated along with 22 others, including his friend and Minister of the Economy, Bassel Fleihan. His assassination set off massive demonstrations (“the Cedar Revolution”) fueled by a widespread belief that Syria was involved in the killing. In June of 2005, credible evidence that Syrian operatives in Lebanon were planning to assassinate prominent anti-Syrian personalities and a “hit list” were made public (Weisman, 2005). Indeed, a string of assassinations followed, including three anti-Syrian journalists in 2005, the Minister of Industry in 2006, and a Member of Parliament on June 13, 2007.

Capitalizing on the outrage in Lebanon and elsewhere in the Middle East over the Hariri assassination and the Syrian dominance of Lebanon, international pressure was placed on Syria to comply with United Nations Resolution 1559 which was passed in September, 2004, and called for the withdrawal of Syrian troops. The Syrian army had entered Lebanon in October 1976, a year after the civil war broke out, when the then Lebanese President (Suleiman Franjieh) with the approval of the Arab League requested its assistance in restoring law and order. On April 26, 2005, the last of the approximately 14,000 Syrian troops left Lebanon, thus ending 29
years of military presence. Syria's intelligence service was widely believed to have held the reins of Lebanese politics during those 29 years and is suspected to be continuing to exercise influence after the troops’ withdrawal (Weisman, 2005).

On July 12, 2006, Israel launched an extensive military attack on Lebanon after Hezbollah militia fighters abducted two Israeli soldiers. This ignited a 34-day war that caused an estimated $3.6 billion in infrastructure damage and killed approximately 1,200 Lebanese civilians. In the heat of this war, the former prime minister of Lebanon, Dr. Salim Al Hoss, wrote an impassioned open letter to President George W. Bush which epitomized the Lebanese people’s feelings about the disproportionate Israeli reaction to the kidnapping of two soldiers. The following is an excerpt from the letter that was published in the Daily Star on August 3, 2006.

We heard you express your regrets regarding the casualties of Israel's ravaging war against my country, Lebanon.

I hope you have been furnished with a true profile of the atrocities being perpetrated in my country. . . .

Israel is wantonly indulging in the most horrendous forms of terrorism in Lebanon: indiscriminately killing innocent civilians at random; not sparing children, elderly or handicapped people; demolishing buildings over their residents' heads; and destroying all infrastructure, roads, bridges, water and power arteries, harbors, air strips and storage facilities. Nothing moving on the highways is spared, not even ambulances, trucks, trailers, cars or even motorcycles, all in violation of the Geneva Conventions and human rights.

The displaced population has reached more than one fourth of the total population of my country—all suffering the harshest and most miserable of conditions. The victims include thousands of killed and maimed.

If this is not terrorism, what is?

Israel's savage assault has been labeled retribution for Hizbullah's abduction of two Israeli soldiers. This smacks of collective punishment, which constitutes a brazen violation of the Geneva Conventions and human rights. Furthermore, the alibi is far from plausible. The two Israeli soldiers were abducted for the express purpose of reaching a swap of hostages with Israel. In fact, Israel had acceded more than once to such swaps in the past. Why would a swap of prisoners be acceptable at one time and a taboo, rather a casus belli, at another? This created a conviction among the Lebanese that the sweeping assault against them was premeditated, and the abduction was only a tenuous excuse.

Israel is indulging in terrorism at its worst, at its ugliest, using the most lethal and sophisticated weapons you have supplied them.

We the Lebanese are justified in seeing in Israel as a most atrocious terrorist power, and seeing in you a direct partner. Mr. President: You are indeed a terrorist practicing the
worst variant of terrorism as you condone the annihilation of my country, precluding a cease-fire to be announced, supporting the aggression against my people politically and diplomatically and bolstering Israel's destructive arsenal with the most lethal weaponry.

You repeatedly claim that Israel is acting in self-defense. How preposterous! Self-defense on other people's occupied territory is tantamount to one thing: blatant aggression.

You call Hizbullah a terrorist organization. We call it a legitimate resistance movement. There would have been no military wing of Hizbullah if there had been no Lebanese territory under Israeli occupation, if there had been no Lebanese hostages languishing in Israeli jails, and if Lebanon had not been exposed to almost daily Israeli intrusions into its airspace and territorial waters, and to sporadic incursions into Lebanese land and bombardment of civilian targets.

You cannot eliminate a party by demolishing a whole country. This would have been achieved peacefully by Israel withdrawing from the land it occupies, releasing Lebanese prisoners, and desisting from further acts of aggression against Lebanon. . . . (Al Hoss, 2006)

Less than a year after the July 2006 Israeli-Hezbollah conflict, in his op-ed article entitled “Give the Arab Peace Initiative a Chance” which was published in the New York Times on May 11, 2007, the then (since June 30, 2005) Prime Minister of Lebanon, Fuad Siniora, described the damage inflicted upon Lebanon, reflected on its consequences, and highlighted the regional context for the conflict. He concluded that diplomacy—not force—is the only option to resolve the conflict and to prevent further violence.

Last week, Israel's Winograd Commission published an interim report scrutinizing Israel's conduct during what it called the country's most recent military "campaign." But the report failed to draw the most essential lesson from the July war and the wars that preceded it: military action does not give the people of Israel security. On the contrary, it compromises it. The only way for the people of Israel and the Arab world to achieve stability and security is through a comprehensive peace settlement to the overarching Arab-Israeli conflict.

Last summer’s war was only the latest eruption of violence in this enduring conflict, and hindered prospects for peace rather than creating opportunities for it. The Winograd interim report criticized the Israeli government's war goals as being unclear and unachievable, yet the Israeli Army came dangerously close to achieving the stated goal of

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2 - An Israeli governmental commission of examination, chaired by former Justice Dr. Eliyahu Winograd, was appointed on September 17, 2006: "To look into the preparation and conduct of the political and the security levels concerning all the dimensions of the Northern Campaign which started on July 12th 2006." On April 30, 2007, the classified interim report was submitted to the Prime Minister (Ehud Olmert) and the unclassified report was posted, on the Israel Ministry of Foreign Affairs website: (www.mfa.gov.il/MFA/Government/Communiques/2007/Winograd+Inquiry+Commission+submits+Interim+Report+30-Apr-2007.htm).
its chief of staff, Lt. Gen. Dan Halutz: to "turn Lebanon's clock back 20 years."

The report made no mention of the sheer damage inflicted. Lebanon's airports, bridges and power plants were systematically ravaged. Villages were destroyed, and more than an eighth of its population displaced. The bombardment caused an estimated $7 billion in damage and economic losses while leaving behind 1.2 million cluster bomblets\(^3\) that continue to kill and maim innocent people.

Most important, the war took the lives of more than 1,200 Lebanese citizens, the vast majority of them civilians. This epitomizes the protracted injustice Arabs feel as a result of Israel's record of destruction of their lives and livelihood, its oppression of the Palestinian people and its continued illegal occupation of Arab lands. The July war proved that militarism and revenge are not the answer to instability; compromise and diplomacy are.

This should be the impetus for Israel to seek a comprehensive solution based on the Arab Peace Initiative. The Winograd Commission's failure to discuss the war's implications for peace prospects leads one to wonder whether Israel would rather allow this conflict to fester as long as it is under relatively controlled conditions. Its goal should be regional peace and security, which can be realized only through a just resolution to the Arab-Israeli conflict. The inevitable alternative is increased extremism, intolerance and destruction.

Like the Israelis, the Arab people have legitimate security concerns, as evidenced by what Lebanon endured last summer. So often we have seen parties to the conflict use force in the name of self-defense and security, only to further aggravate the situation and compromise the very security they seek. These escalations also occur because there has never been full compliance with international law. Thus, illegal occupations, over-flights, detentions, house demolitions, humiliating checkpoints, attacks and counterattacks continue to heighten the anger and despair. Perpetuating hostility and distrust in this manner goes against the tide of confidence-building this region needs to foster stability. The conflict has persisted for so long, generating so many tangled consequences, that diplomacy remains the only option. . . (Siniora, 2007)

On June 30, 2007, United Nations Secretary General, Ban Ki-moon, released his fourth report on Security Council Resolution 1701 that ended the summer 2006 conflict between Israel and

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\(^3\) Save the Children Sweden reported that according to the UN and Lebanese officials, most of the more than a million cluster bombs Israel dropped over south Lebanon during the last three days of the summer 2006 war, “are attractively shaped and brightly colored like toys” (Daily Star, 7/23/2007). According to the national demining office, most of the victims of the unexploded ordnance are children. Six children were killed and 68 injured in less than a year since the summer 2006 war. This prompted an explosive remnants awareness campaign that included 100 billboards posted around Lebanon and two 40-second animation television spots. The campaign was funded by the Canadian International Development Agency through Save the Children Canada in collaboration with the Lebanese demining office, the Landmine Resource Center at Balamand University, and Spacetoon channel (Daily Star, 7/23/2007).
Hezbollah. He expressed his dismay over the ongoing political turmoil in Lebanon and Israel's continual violations of the resolution:

I am deeply concerned that Lebanon remains in the midst of a debilitating political crisis and faces ongoing attacks aimed at destabilizing and undermining its sovereignty, territorial integrity and independence . . . .

Against this background, I am concerned that continued implementation of Resolution 1701 may face repeated difficulties. Greater progress is necessary on key issues that are central to the achievement of a permanent cease-fire and a longer-term solution, such as the release of the abducted Israeli soldiers and of the Lebanese prisoners, the enforcement of the arms embargo, the halting of Israeli air violations of Lebanese sovereignty and the Shabaa Farms issue. (Daily Star, June 30, 2007)

In this report, Ban Ki-Moon also urged Israel, once again, to provide exact information regarding the location of the landmines and the more than a million cluster bombs that it dropped on Lebanese soil, during the last three days of the war, prior to the cease-fire declaration.

The provision of such information to UNIFIL would greatly assist the United Nations Mine Action Coordination Center in its efforts to clean up the estimated 1 million unexploded cluster munitions . . . .

Continuing deaths and injuries to Lebanese civilians caused by these munitions, not to mention the loss of agricultural production in affected areas, only increases the local population's antagonism toward Israel. I again urge Israel to provide detailed data on its use of cluster munitions to the United Nations as soon as possible. (Daily Star, June 30, 2007)

In addition to the above-mentioned consequences of the summer 2006 war, two relatively less publicized, but just as devastating effects, were the environmental damage (Daily Star, 7/14/2007; 7/17/2007) caused by Israeli attacks on Lebanese power plants and the apparent deliberate destruction of more than 20 publishing houses and research institutes, i.e., the collateral “war on intellectual life” (Hodeib, 2007).

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4 - According to several political analysts (e.g., Lamb, 2007) “Israel to this date has not complied with SCR [Security Council Resolution] 425, 1701 or more than 30 other UN Resolutions”

5 - UNIFIL, United Nations Interim Force in Lebanon is an international peace-keeping force that was originally created by the Security Council in 1978 to monitor the Israeli-Lebanese border. Following the July/August 2006 crisis, its mandate and size were expanded (www.un.org/Depts/dpko/missions/unifil).

6 - “A year after the environmental crisis precipitated by the Israeli air strikes on the Jiyyeh power plant, environmental experts say that the pollution still remains. The strikes caused oil spills that covered the Lebanese coastline. Around 15,000 tons of crude oil polluted Lebanese shores and caused serious impacts on human health, biodiversity, fisheries and tourism. . . . The Mediterranean, only 0.7 percent of the world's oceans, is one of the richest seas for biodiversity in the world—hosting 7.5 percent of the world's marine animals and 18 percent of its flora” (Daily Star, 7/14/2007).

7 - Lebanon’s publishing houses produce 60 to 75% of Arab books (Hodeib, 2007).
Although the summer 2006 war’s catastrophic damage drew the Lebanese together, and increased the popularity and status of Hezbollah, a political deadlock soon developed. A Hezbollah-led opposition—which includes the Shiite party Amal and the followers of the Christian general Michel Aoun—began a sit-in on Dec. 1, 2006 in central Beirut. The goal was to force the government to resign. Since the government was still in power, central Beirut remained paralyzed by the demonstrators. The prime minister and others were living in their offices on a hill overlooking hundreds of pitched tents. Approximately 12 Members of Parliament, fearful they might be killed, left the country. Some United Nations officials moved from their heavily guarded offices in central Beirut to less exposed, more secure locations. In their article published in the New York Times on July 7, 2007, Mekhennet, Moss, and Slackman (2007) wrote: “Today, the Lebanese are increasingly divided by rolls of razor wire spread across roads and wrapped around buildings and homes. They are separated by military checkpoints that tie up traffic.”

Less than a year after the summer 2006 war, on May 20, 2007, Fatah al-Islam, an Al-Qaeda inspired group of militants composed of mostly non-Lebanese members, “took up again Israel’s dirty work.” According to a statement issued by the Lebanese Army’s press office and published in the Daily Star on July 13, 2007, “What Israel was not able to destroy during its 34-day war against Lebanon; Fatah al-Islam is currently destroying.” The fighting, which was described as the worst internal fighting since the 1975-1990 civil war, continued for a total of 106 days until the Lebanese Army subdued this group of militants on September 2, 2007 in the Nahr al-Barid Palestinian refugee camp, winning a decisive victory, but destroying the camp and displacing its 30,000 Palestinian residents (Daily Star, 11/17/07).

The political and social repercussions of that conflict along with the nearly year-long political impasse created by the sit-in in central Beirut, were augmented by the Lebanese Parliament’s inability to agree on a successor to President Emile Lahoud, whose term ended on November 23, 2007 (Daily Star, 11/17/07). This created a political vacuum for several months and prompted several political analysts to paint a dire picture of the political situation in the country.

After the outbreak of street fighting in May 2008, in which Hezbollah gunmen fought their opponents across Beirut, a new power-sharing agreement was reached that gave the Shiite militia more power and Lebanon’s Parliament elected Army Commander, General Michel Suleiman as president on May 25, 2008. As a sign of confidence in the government the US began a new wave of aid to the Lebanese military, the first since the 1980s (New York Times, 9/29/2009).

The latest round of struggle between the nation's political groups played out in the parliamentary elections of June 2009. The hotly contested race, which was viewed as a fight between Tehran and Washington for influence in the Middle East, was considered to be the freest and most competitive to be held in decades, but it was also the most corrupt. The American-backed alliance, known as the March 14 coalition (a predominantly Sunni, Christian, and Druze alliance), won the majority in the 128-member parliament with 71 seats, compared to 57 for the Hezbollah-led coalition, and thus retained control of the Lebanese Parliament. On June 29, 2009, President Suleiman named Saad Hariri (Rafiq Hariri’s son) the next prime minister. It took Hariri more than four months to assemble a national-unity cabinet that includes members of the
opposition because of intense bargaining on the portfolios between rival blocks. The Lebanese Parliament approved the 30-member cabinet on December 11, 2009. As a result, barring interference from neighboring countries, the nation entered a period of political calm and stability.

Population and Culture

**Number, ethnicity, and religious sects.** Lebanon’s population was estimated to be about 4.3 million in 2000 (Embassy of Lebanon, Washington DC, 2007), of whom 95% are Arab, 4% are Armenian, and 1% are of other ethnic origins (CIA, 2007). It comprises a “kaleidoscope” (Harris, 1997, p.60) of 17 officially recognized Christian and Islamic communities (sects) which are “highly differentiated despite the Arab ethnicity and Arabic language of the overwhelming majority” (Harris, 1997, p.3). According to the CIA World Factbook (2007), the religious distribution of the population is as follows: Muslim 59.7% (Shi’a, Sunni, Druze, Isma’ilite, Alawite or Nusayri), Christian 39% (Maronite Catholic, Greek Orthodox, Melkite Catholic, Armenian Orthodox, Syrian Catholic, Armenian Catholic, Syrian Orthodox, Roman Catholic, Chaldean, Assyrian, Copt, Protestant), and other (1.3%). The largest Muslim group is the Shi’a, followed by the Sunni, and the Druze. The largest Christian group is the Maronite Catholic, followed by the Greek Orthodox, and the Melkite Catholic. It is noteworthy that the percentage of Christians in Lebanon is larger than in any other Arab country, where it never exceeds 15% (Harris, 1997, p.60).

**Fertility rate and age structure.** Although the rate of procreation varies according to religious community⁸, the total fertility rate (births per woman) is currently estimated to be 1.88 (CIA, 2007) and the annual population growth rate is estimated to be 1.2 for the years 2000-2005 (United Nations Development Program [UNDP], 2004, p. 153). The age structure of the population is as follows: (a) Birth to age 4: 12.3%, (b) Ages 5-14: 21.8%, (c) Ages 15-24: 20%, (d) Ages 25-64: 40.4% and (e) ages 65 and above: 5.5 % (Embassy of Lebanon, Washington DC, July 2007). The median age is 28.3 years (CIA, 2007).

**Disability.** The incidence of disabilities in Lebanon is not ascertained. The Central Administration of Statistics, based on a study conducted in 1998 (results reported in Council for Development and Reconstruction [CDR], 2003) determined an approximate disability rate of 1.5%, i.e., around 60,000 persons with disabilities, of whom more than 50,000 below 60 years of age, with a higher number of males than females (1.8% to 1.1%), especially in the 15 to 44 age range. CDR observed that the 1.5% rate is considerably lower than the 4% rate used by the Ministry of Social Affairs (MoSA), which is the governmental body in charge of disability issues, and the 10% rate used by the United Nations (UN). It should be noted here that no legal definitions of disabilities exist and no uniform system of classification is used.

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⁸ - Christian families tend to be smaller than Muslim families. According to a survey conducted in 1970, the average Lebanese Christian family excluding Maronites had 3.7 children, the Sunni family had 4.38 children, and the Shi’a family had 5.01 children. However, economic difficulties associated with the civil war and its aftermath resulted in an appreciable decline in the size of the average Lebanese family (Collelo, 1987).
Regarding the etiology of disabilities in Lebanon, MoSA provides the following estimates: 32% are congenital, 35% are caused by diseases, 15% are caused by accidents, 12% are caused by war, and 6% are caused by other factors (reported in Spapperi, 2002, p. 7).

**Family.** The primacy of the family manifests itself in all aspects of Lebanese life. According to Khalaf (1987) Lebanon’s twentieth-century history has demonstrated that a population’s adjustment to modern urban living need not diminish the “primordial” ties of family, village, and sect. Kinsmen combine forces to protect, support, and provide opportunities to their family members. To a certain extent, a family’s status determines its members’ access to education as well as their chances for achieving prominence and wealth (Collelo, 1987).

Although the reactions of Lebanese families to living with and caring for a child with a disability have not been systematically investigated, some insights could be gleaned from the stories collected by Helle Mittler (1995). Six of the 18 comments by Lebanese parents included in her book, praise the personal qualities of the family member with a disability and emphasize their positive contributions to family life (spreading happiness and love; teaching patience and open-mindedness; strengthening family bonds; promoting support). However, the majority of comments expressed the parents’ frustration at their inability to adequately help their child, emphasized the difficulties they face, complained about society’s unfair treatment, and considered disability not only as a misfortune, but as shameful and embarrassing. Boukhari’s (1997) account of her work with Lebanese mothers of children with cognitive disabilities confirmed this more prevalent viewpoint and described the impact of the birth of a child with a disability on the Lebanese family as follows:

The husband’s family is likely to blame the misfortune on the mother: “it is her [family’s] bad seed . . . .” In addition to bringing shame to the family, the birth of a disabled child is likely to consign his or her mother to a lifetime of misery, since the belief in the mother’s culpability is used to justify a lack of practical support to the child and mother on the part of the husband and extended family. After all, isn’t it the mother’s fault in the first place? Many of the women we know are deeply convinced that they should feel this guilt, and that they should atone for it until the end of their lives. If the mother dies, one of the daughters must take over the burden of shame and responsibility (p. 37).

Boukhari (1997, p.36) attributes the problems encountered by woman carers not to the disability itself, but to the “age-old system which oppresses women, puts them in an inferior position to men in their households, and blames them for anything that goes wrong, including the birth of a disabled child.”

**Gender.** Despite the patriarchal family structure, the persistence of traditional family roles (i.e., roles of women restricted to those of mother and homemaker), and the variety of religious community attitudes regarding gender roles, Lebanon’s Gender-Related Development Index’s value is 0.755 with a rank of 64 among the 144 countries studied (UNDP, 2004, p. 218). Lebanese women have enjoyed equal civil and political rights since 1952 when they were granted the right to vote and to stand for election (UNDP, 2004, p. 235). They have a high adult literacy rate [81% vs. 92.4% for men (UNDP, 2004, p. 218)] and attend institutions of higher education in large numbers [for example women constituted 41% of the student body at the
American University of Beirut in 1983 (Collelo, 1987)]. They have their own organizations [e.g., National Committee of Women (Khalaf, 2002)], participate in the work force [ratio of estimated female to male earned income is 0.31 (UNDP, 2004, p. 222)], and hold elected political office [2.3% of seats in parliament are currently held by women (UNDP, 2004, p. 222 & 235)].

Lebanon has ratified a number of international conventions that protect the rights of women [e.g., Convention on the elimination of all forms of discrimination against women, 1979 (UNDP, 2004, p.239), and International Labor Organization (ILO) Elimination of discrimination in respect of employment and occupation, 1996, (UNDP, 2004, p.243)] but, there are discriminatory aspects of Lebanese law that prevent their full implementation (Khalaf, 2002).

**Urban.** Since the majority of resources are centralized, the Lebanese population is concentrated around the capital Beirut and a few other cities: Tripoli and Byblos in the north, Sidon and Tyre in the South, and Zahleh in the Beka’ valley. One Lebanese in two lives in greater Beirut, and more than two out of three live in the other cities or large towns (Davie, 2002). In 2002, 87.2% of the Lebanese population was considered urban and that percentage is projected to increase to 90.1% in 2015 (UNDP, 2004, p. 153).

**Languages.** Arabic is the official language of Lebanon, but French and English are widely spoken. Armenian is also spoken by a minority group. Most Lebanese people are bilingual and they tend to use a mixture of two or three languages when expressing themselves orally. Even people with minimal literacy skills can get by in at least one foreign language.

**Freedom of speech.** Lebanon has a free press and enjoys a long tradition of freedom of expression. Major local newspapers are published in the three most commonly used languages—Arabic, English, and French—and include An Nahar, As Safir, Al Hayat, the Daily Star, and L’Orient-Le Jour. In addition, newsagents stock an assortment of newspapers as well as weekly magazines from all over the world. The local mass media (radio and television) also broadcast in different languages, with some stations transmitting exclusively in one language. The newscasts on a few of these stations are also provided in Armenian. Simultaneous sign language interpretation is available for televised newscasts on certain channels. It is worth mentioning here that, according to Haidar (2002), Lebanon is the only Arab country with private television and radio stations and that even its government’s television and radio stations air opposing views.

**Development**

The most recent Human Development Report (UNDP, 2006, 283-285) ranked Lebanon in the medium human development range with a Human Development Index (HDI) value of 0.774 and a rank of 78. The HDI is a composite index that measures the average achievements of a country in three basic dimensions of human development: Health (life expectancy at birth), educational attainment (adult literacy and school enrollment rates), and standard of living (adjusted real income). HDIs for this report were calculated using data from the year 2004, obtained from 177 UN member countries (16 UN member countries were not included because of lack of data). Then these countries were ranked according to HDIs, from the highest HDI value 0.965
(Norway) to the lowest HDI value 0.311 (Niger). Lebanon’s HDI value is higher than the average HDI values for the world (0.741), for countries in the medium human development range (0.701), and for Arab States (0.680). A trend analysis revealed a steady increase in HDI value since 1990 when its value was 0.673 (UNDP, 2006).

**Government**

The Republic of Lebanon gained its independence from the League of Nations’ mandate under French administration on November 22, 1943. It is a parliamentary “confessional democracy” (Harris, 1997, p. 2) in which political power is apportioned on a sectarian basis. There are seven major sectarian communities, belonging to two tiers according to demographic and political weight: “Three ‘great’ communities—the Shi’i Muslims, the Maronite Christians, and the Sunni Muslims—. . . hold the principal regime offices . . . . Four other communities—in descending demographic order: Orthodox Christians, Druze, Greek [Melkite] Catholics, and Armenians—occupy a second tier, with subsidiary stakes in the regime” (Harris, 1997, p. 68). Political leadership is distributed and perpetuated through “political families” who have monopolized the representation of certain sects for over a century (Collelo, 1987). Several political parties and groupings exist, consisting of individual political figures and followers motivated by religious, clan, and economic considerations (CIA, 2007).

The Lebanese constitution drafted on May 23, 1926, was amended a number of times, most recently by the Charter of Lebanese Reconciliation (Al Ta’if Accord) of October 1989. The Al Ta’if Accord established a more equitable political system, “particularly by giving Muslims a greater say in the political process while institutionalizing sectarian divisions in the government” (CIA, 2007).

As a democratic republic, Lebanon has a parliamentary system of government with a Maronite Catholic President (Currently Michel Suleiman), a Sunni Muslim Prime Minister (currently, Saad Hariri), a Greek Orthodox Deputy Prime Minister (currently, Elias Al Murr), a cabinet (executive branch, currently, 30 ministers), a Shi’a Muslim Speaker of the House (currently, Nabih Berri) and a 128-member Parliament (legislative branch) elected by universal adult suffrage.

Since the end of the 1975-1990 war Lebanon has conducted several successful elections and beginning in August 2006, the Lebanese Armed Forces extended central government authority throughout the country (CIA, 2010).

**Economy**

Lebanon's once thriving free market economy which was devastated by the 15-year civil war, was further hindered by the summer 2006 war and the continuing political turmoil. According to the CIA *World Factbook* (2010):
The Lebanese economy is especially affected by political turmoil because it is based primarily on the services and banking sectors, which account for approximately 76.2% of the Gross Domestic Product (GDP) (CIA, 2010). Major sub sectors of services are commerce, tourism, and financial services (banking and insurance). Other components include health care and higher education (Embassy of Lebanon, Washington DC, 2007). The industry and agriculture sectors of the economy account for only 18.7% and 5.1% of the GDP, respectively (CIA, 2010). The GDP per capita Purchasing Power Parity (PPP) was estimated to be US$ 10,700 for 2007, US$ 11,300 for 2008, and US$ 11,500 for 2009 (CIA, 2010). Although the GDP per capita PPP is not considered to be a direct measure of quality of life, it could be useful for comparing living standards between countries. Lebanon was determined to fall below the world average GDP per capita PPP and was assigned the rank of 57th among 181 economies rated by the International Monetary fund in 2009, 60th among 166 economies rated by the World Bank in 2008, and 74 among 193 economies rated by the CIA in 2010 (Wikipedia, 2010).

In his analysis of the socio-economics of Lebanese government budgets, Gaspard (2004a; 2004b) pointed out that although increasing government expenditures and the associated mounting debt were necessary to address serious deficiencies and to launch economic growth, only a small share of the government debt has financed expenditures on investment or basic social services (health, education, and social affairs) which should have been high priorities for government spending and debt. According to him, Non Governmental Organizations (NGOs) and other non-profit organizations play an important role in providing those services and thus compensate for the inadequate or absent government role in this domain. Government budget transfers to these organizations could therefore significantly contribute to social and political stability. However,

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9 - Lebanon’s remarkable banking sector is considered to be one of the most efficient in the world (Arab.net, 2007).
these transfers have stayed at relatively low levels (0.5-0.6% of GDP, i.e., less than 2% of budget expenditures). He concluded that the increase in government debt, the fairly small economic growth, and the decreasing real incomes of the majority of the people do not advance Lebanon’s economic and social prospects.

Lebanon’s well-educated, multi-lingual, multi-talented workforce (Embassy of Lebanon, Washington DC, 2007) is plagued by unemployment (estimated rate was 20% for 2006; CIA, 2007) and the declining purchasing power of wages. The gap between the rich and the poor has widened since the end of the civil war, resulting in grassroots dissatisfaction over the skewed distribution of wealth. In his analysis of the economic situation in Lebanon presented at a forum on the topic held in 2004, Elie Yashou, Dean of the School of Business Administration at Notre Dame University, Louaize, stated that funds flowing from Lebanese expatriates play a crucial role in preventing the collapse of the Lebanese economy (reported in Hourani, 2004). According to him, while less than 10% of the Lebanese population enjoys total economic bliss, more than 90% lives below the poverty line. He recommended raising the minimum wage, which was then $200 per month to at least $600, which he claimed is the minimum amount needed for a person to stay above the poverty line.

**Education**

Lebanon has one of the highest literacy rates [91% (Embassy of Lebanon, Washington DC, 2007)] in the Middle East. Private agencies whether secular or religious, local or foreign (mainly American, British, French, & German), have been historically responsible for providing most of preschool, elementary, and secondary education programs. Less than 35% of Lebanon’s children attend public schools (Haidar, 2002). All schools are bilingual, with Arabic as the first language and French or English as the second language. The foreign language is introduced along with Arabic in nursery school. In the upper elementary and secondary grades, the foreign language becomes the language of instruction for most subjects (Shaaban, 1997) and a second foreign language is added. An increasing number of schools are introducing a second foreign language at the primary level (e.g., schools run by the German Cultural Center). All schools implement the basic curriculum prescribed by the Lebanese government as a minimum requirement; they then supplement this curriculum with subjects pertinent to the goals of the individual school (Haidar, 2002). With the adoption of the new national curriculum in 1998, the traditional system of education based on rote learning and cramming of information is being slowly replaced by a system that promotes autonomous learning, thinking skills, and communicative competence. Private schools compete to attract the best students and exclude those who could reflect negatively on the school’s image and performance profile, namely children with special needs.

**Special education.** In Lebanon, as elsewhere, disability issues have traditionally been conceptualized through a social model of charity and welfare. As such responses to the needs of people with disabilities have centered on specialized service provision, largely carried out by charitable or other NGOs. This conceptualization together with the predominant medically-oriented service model that emphasizes care and therapy at the expense of functional and independent living skills, have perpetuated the segregation of children with disabilities. These
children are generally not accepted in public or private schools. They are automatically referred to MoSA, which is the governmental organization in charge of programs and services for individuals with disabilities, and placed in special programs run by NGOs, which currently monopolize the provision of services for children with disabilities. Before the civil war, a few such programs were available. Although the quality of the services they offered was questionable, they were highly regarded pioneer efforts for the Arab region. Some of these programs are residential and continue to serve children with disabilities from several Arab countries. In 1998, the majority of MoSA’s disability budget was transferred to 46 care centers run by NGOs that provide various services to 5,700 individuals with disabilities, including shelter, food, rehabilitation, and vocational training (CDR, 2003). Of the 46 care centers, 36 are located in Beirut and Mount Lebanon, seven are in the south, and three are in the Beka’ valley. Needless to say, the services provided by these NGOs are too restricted in range to be responsive to the variety of special needs and not extensive enough to meet the country's demand. There is no coordination of efforts between NGOs, no accountability, and no monitoring of program quality. In fact, little information is available about these programs and about the number of children who do not receive any services at all.

In 1998, a few parents of children with Down syndrome (DS) who were not satisfied with the limited service delivery options for their children, created the Lebanese Down Syndrome Association (LDSA), a registered NGO, in order to advocate for their children’s rights. One of the main issues they focused on from the start was inclusion of children with DS in typical schools. With the cooperation of a newly established small private school (Heritage College, which at that time had a total of 125 students, nursery through middle school) they began by arranging for five children with DS to be fully included, one per classroom, in the preschool and primary cycles (Nursery, KGI, KGII, Grades 1 and 2) during the 1998-99 school year. LDSA supported the school by fundraising to cover the cost of an in-service teacher training program that included weekly in-class follow-up and group problem-solving sessions. LDSA also helped the parents of the five children enrolled, by arranging for discounted rates for related services (Speech and Language Therapy, Occupational Therapy, and Positive Behavioral Support) and partially defraying the high cost of tuition fees, as needed. Although LDSA’s financial backing was withdrawn gradually, this pioneer full inclusion program continues to successfully meet the educational needs of children with a variety of disabilities. It is currently in its 12th year of operation and is providing increased access to and participation in typical school environment and curriculum, improved educational achievement and social skills, enhanced community living and employment potentials, thus a better quality of life for 40 students with disabilities, among whom 25 are students with intellectual disabilities (7 with Down syndrome). Over time, the total number of students with disabilities who benefited from Heritage College’s program is approximately 6010. Two other advocacy organizations, also registered as NGOs, the Lebanese Physical [sic.] Handicapped Union (LPHU) and Youth Association for the Blind (YAB) were also promoting and implementing inclusive educational practices during that same period. Motivated by the demonstrated effectiveness of these programs a small number of private schools are currently at various stages of providing inclusive education programs for children with disabilities. However, what they define as “inclusion” runs the gamut from mere physical inclusion and associated minimal contact with typical peers to part-time membership in a regular

10 - Heritage College enrollment figures obtained through a personal telephone communication with Leila Haram Raouda, Principal, in November 2009.
classroom without adequate support, perhaps due to lack of awareness of, or commitment to, the basic principles of inclusion. The problem is compounded by the current dearth of teachers and other professionals who espouse the philosophy and believe in the feasibility of inclusion. General education teacher training programs in Lebanon tend to perpetuate segregation practices and until recently the only jobs available for the limited number of special education graduates were in the special programs run by the NGOs.

**Special education teacher training.** There are 13 institutions\(^\text{11}\) of higher education (IHE)\(^\text{12}\) in Lebanon. The three oldest and most prominent are: (1) American University of Beirut (AUB): established in 1866 by American protestant missionaries and affiliated with the university system of the State of New York; (2) Université Saint Joseph (USJ) established in 1875 by French Jesuits and affiliated with the University of Lyon, France; and (3) the Lebanese American University (LAU): established as Beirut College for Women in 1924 by the Presbyterian Board of Foreign Missions. Other universities include the Lebanese University (a public university) established in 1951, Haigazian University established in 1955 by the Armenian Evangelical Churches of the Near East, and the Arab University established in 1960 and affiliated with the University of Alexandria, Egypt. Seven of the 13 IHEs offer education courses, but only four of the seven offer training in special education. AUB (Language of instruction is English) offers a post-Bachelor’s degree teaching diploma in special education. USJ (Language of instruction is French) offers a four-year degree program in special education that espouses an inclusive, participatory, functional approach and requires reading knowledge of English as a prerequisite for graduation. Haigazian University (Language of instruction is English) has a two-year paraprofessional training program on disability issues. LAU (Language of instruction is English) recently added a Masters level program in learning disabilities.

**Future Outlook**

Although the current status of educating children with disabilities in Lebanon appears bleak, a few glimmers of hope do exist and could lead to a brighter future. Reasons for optimism include the following:

**Ratification of international conventions and resolutions.** Lebanon has ratified a number of international conventions that protect the right to education for every individual, beginning with the *Universal Declaration of Human Rights* (1948), through several United Nations declarations, and culminating in the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (1993), which urges countries to ensure that the education of persons with disabilities is an integral part of their educational system. Lebanon also endorsed the *World Declaration on Education for All* (EFA); the resolution of a UNESCO sponsored conference held in Jomtien, Thailand (March 5-9, 1990), which extends the right to education to everyone, regardless of individual differences. In addition, Lebanon sanctioned the

\(^{11}\) Information about the IHEs obtained from their websites and from Kurani (1994).

\(^{12}\) Lebanon’s private universities were the pride of the Middle East before the civil war. These universities made Lebanon the educational center of the region and produced many of its leaders (Haidar, 2002).
Salamanca Statement and Framework for Action on Special Needs Education, adopted at a UNESCO sponsored conference held in Salamanca, Spain (June 7-10, 1994), which affirms that schools should accommodate all children and promotes inclusive education.

Inclusion of exceptionalities in the national educational framework. Educational programs for students with disabilities or for students who are gifted were included in the diagram depicting the new educational framework in Lebanon (Lebanese Ministry of Education, 1997). This was the first time that such programs were mentioned by the Ministry of Education (MoE) since Lebanon became an independent country in 1943. These programs were, however, described in a footnote, as unconventional and distinct from the mainstream.

Support of international organizations. Several international organizations working in Lebanon [including the United Nations Development Program (UNDP) and United Nations Children’s Fund (UNICEF)] lead by the Arab Regional Office of the United Nations Educational Scientific and Cultural Organization (UNESCO) located in Beirut, in conjunction with MoE organized two national conferences on special education (held in April, 1999 and June, 2000) to gather stakeholders’ recommendations and formulate an action plan. Conference follow-up activities to establish committees and assign projects were halted by the appointment of a new Cabinet of Ministers including a new Minister of Education. The UN organizations along with other international organizations (e.g., Save the Children’s UK and Sweden branches) play an important role in facilitating social and educational development in Lebanon.

Promulgation of Lebanese Law 2000/220. After a long struggle, a bill of rights that was drafted by advocacy groups (comprising war-injured and adventitiously disabled individuals) in conjunction with MoSA, was finally promulgated as Law 2000/220, in May 2000. Article 59 of the law guarantees the right to equal educational and learning opportunities for all children and adults with disabilities in public or private general education classrooms. Article 60 of the law asserts that a disability, in and by itself, is not a deterrent to placement in any educational institution. Law 2000/220 also revokes statements in Lebanese law that contradict this position. In addition, it covers rights in other areas including health, housing, sports, employment, and tax exemptions. The prevailing philosophy of the law promotes a generalized environment receptive to the legitimate acceptance and integration of people with disabilities in society.

Unfortunately, however, since this law was promulgated ten years ago, no decrees or regulations have been issued to mandate and facilitate its implementation. Thus, little has changed in the traditional approach of the Lebanese educational sector. Children with disabilities are still generally barred from entering typical private or public schools and they continue to be referred to special centers operated by NGOs under the auspices of MoSA. The justification commonly offered for maintaining the status quo is that neither the teaching staff nor the educational system is ready to implement this new law.

Law 2000/220 sets the stage for a qualitative shift regarding disability issues because it promotes a developmental functional model instead of the prevailing medical model. However, the law keeps MoSA, as the authority responsible for disability issues and appoints a National Committee on Disability Affairs as the executive agency for supervising the implementation of
the law. Advocacy groups have expressed concerns about these two aspects of the law, especially because the current committee consists mainly of representatives of the NGOs which have been monopolizing care services.

**Increased public awareness of disability issues.** In the past few years advocacy groups have stepped-up their public awareness activities which included radio and television interviews or programs on disability issues, press and other media coverage of conference presentations, accomplishments, innovative service delivery options, fund-raising efforts, and even protest manifestations. As a result the voice of self advocates and of advocacy groups has become more prominent.

**Funding of the Community Development Project.** On Aug 4, 2003, three Lebanese disability advocacy groups with strong inclusion agendas (LDSA, LPHU, and YAB) along with Save the Children-Sweden’s, Middle East and North Africa (MENA) office in Beirut, jointly (under the name Inclusion Network) submitted a grant proposal in response to a Council for Development and Reconstruction request for proposals (CDR RPF#: CDP/TH2) for a two-year project to promote inclusive practices for individuals with disabilities. Despite competition from several single, or coalitions of, long-established care NGOs, the Inclusion Network was selected in May 2004, as the recipient of the $800,000 two-year grant (loan from the International Bank for Reconstruction and Development—World Bank) towards the cost of implementing the proposed community development project that became known as the National Inclusion Project (NIP). The NIP\(^\text{13}\) consisted of two phases. The first phase, the social assessment phase (duration 6 months), was initiated in June, 2004. It revealed the absence of a culture of inclusion, a lack of legislation (except for Law 2000/220) or national inclusive education policies, the presence of 18 inclusive education initiatives, the prominent role played by advocacy organizations, and the lack of coordination of efforts. The second phase’s (2005-2007) goal was to develop an infrastructure for inclusion in three domains: (1) the social domain; (2) the educational domain; and (3) the vocational domain. A pilot study was conducted in 10 private schools. This resulted in training 120 teachers, 10 principals, 5 social workers, and many school employees, therapists or other specialists, and NGO members. The accomplishments of the second phase included the publication of four guidebooks (inclusive schools, curriculum modification and adaptation, early intervention, and educational and social inclusion), two studies (a statistical portrait of disability in Lebanon, tasks and suggested administrative framework for educational inclusion), and a set of recommendations that constitute a plan of action for inclusion. In addition a public awareness campaign to promote the culture of inclusion was launched that included awareness sessions for students and parents, radio and television interviews and programs, and dissemination of posters and of a special issue of the *An Nahar* newspaper’s supplement on inclusion. A third phase, which was not part of the original project and was, therefore, not funded, was added by the organizations involved in the first two phases. Its goal was to improve educational services, to train staff and students, and to equip 10 public schools to meet the learning needs of a diverse student population, including students with disabilities. Planning for that phase started in July, 2007, and its implementation began in April,

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13 - Summary of the information provided by Amer Makarem (2009), Director of the National Inclusion Project (www. inclusiononline.org) and President of the Youth Association of the Blind, during his presentation about the project at the regional conference on Inclusive Education and Diversity in Early Years, held in Beirut, Lebanon, November 5-7, 2009.
2008. As a result, students with visual disabilities have been included in two public schools since the 2008-2009 academic year. The project is ongoing, although it is hindered by communication challenges between the Ministry, school administration, and teaching staff levels.

**Publication of the Inclusive Schools Guidebook.** This guidebook (Nadjarian, 2008) was developed through a project concerning marginalized children and youth that was initiated by the Lebanese Autism Society in partnership with Caritas-Lebanon, Friends of the Disabled Association, and the Al Hadi Association. It was funded by the European Commission and managed by the Office of the Minister of State for Administrative Reform. Its goal was to conduct a comprehensive survey of inclusive programs during the 2007-2008 academic year and to compile a database of programs that serve the needs of children with disabilities throughout Lebanon. It provides basic information about (a) 41 inclusive private schools and (b) 2 special classes in private schools established and monitored by NGOs that advocate for inclusion. It also lists the associations that could help parents find inclusive programs for their children. Unfortunately, participants in the current study reported that the information provided in this guidebook is already outdated because most of the programs listed are either not truly inclusive or they are no longer accepting students with disabilities.

**Funding of the National Inclusion Program in Lebanon (NIPL)**. NIPL is a joint project between the Ministry of Social Affairs, the Ministry of Education and Higher Education, and the Lebanese Institute of Educators at Saint Joseph University. It is a two-year project that started in March, 2009, and is funded by the Italian government. It consists of two sub-projects:

1. **A macro intervention**: The development of a national school inclusion policy, based on children’s rights and EFA principles that guarantees the right of all children with special needs (disability, disorder, difficulty, or illness) to learn and to actively participate in school life.

2. **A micro intervention**: The implementation of a pilot project that supports the inclusion of children experiencing learning difficulties in 11 public schools in different regions, in order to identify key factors and challenges that will inform the policy development process.

**Conclusion of future outlook.** What is encouraging is the fact that most of the above-mentioned positive developments were accomplished while Lebanon was emerging from war and experiencing political unrest coupled with economic problems. Although, the enactment of Law 2000/220 is a significant milestone and a necessary condition for affirming the rights of people with disabilities and promoting their integration in Lebanese society, it is not sufficient for empowering this disadvantaged group. What is needed is the eventual full acceptance of the legislation by mainstream society. The seeds of reform have definitely been planted, and what is required now is persistence and untiring efforts to promote the development of an equitable

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14 - Summary of information presented by Hala Raad (2009), Director of the National Inclusion Program in Lebanon (www.nip-lebanon.com), at the Regional Conference on Inclusive Education and Diversity in Early Years, held in Beirut, Lebanon, November 5-7, 2009.
system of service delivery and support for people with disabilities built on self advocates’ and parents’ perspectives.

Attitude toward People with Disabilities

However, despite the glimmers of hope discussed above, Lebanese people with disabilities appear to be a long way from achieving their rights as illustrated by the following two well publicized incidents that exemplify the current zeitgeist:

Manifestation in front of the House of Parliament. On June 16, 2004, the Lebanese Physical [sic] Handicapped Union (LPHU) was joined by 50 civil organizations (including human rights, disability, women’s, parents’, and victims of war & torture advocacy organizations) in a demonstration to demand an explanation for the lack of progress in implementing Law 2000/220 four years after it was enacted. Their press release (Sylvana Lakkis, June 15, 2004, personal e-mail communication) entitled “Rescuing disabled people from poverty and marginalization” included the following statements:

We have the right to work, to live with dignity and independently
We have the right to have social security and social pension
We have the right to have an environment free of architectural barriers
We have the right to be educated and to be integrated in mainstream schools
We have the right to be respected by others
We will not hide ourselves, because we have different skills in different fields which enable us to work in all sectors

“No people with disabilities allowed on premises.” Noor a ten-year-old girl with Down syndrome was denied entry into a beach resort (Bellevue) south of Beirut during the weekend of July 3-4, 2004. A prominent sign posted at the entrance of the resort states: “people with cognitive disabilities are not allowed on premises”. Noor, who had brought all her water toys along and was looking forward to spending a day at the beach, was visibly disappointed and distressed. She could not understand why they had to leave since she was unable to read the sign. Many Advocacy groups issued statements deploring this blatant denial of rights protected by the Convention on the Rights of the Child (1989) and by Lebanese Law 2000/220 (e. g., Family Planning Association, Lebanese Association for the Rights of the Disabled; LDSA, LPHU, Lebanese Union of Associations for Mental Disabilities(LUAMD)). Several articles were written about the case in Lebanese newspapers (e. g., An Nahar, 2004; As Safir, 2004). The director of the Specialized Care for the Disabled section of the Ministry of Social Affairs (MoSA) visited the beach resort to investigate the case and to inform its administration that it was out of compliance with Law 2000/220. The resort’s manager refused to remove the sign or discuss the matter. His justification was that the previous summer a girl with a cognitive disability was injured in the pool and he had to transport her to the hospital and pay for her treatment. MoSA’s Director General issued a press release stating that since MoSA has no authority to take any action against the resort, the case will be referred to the National Committee on Disability Affairs for it to determine the appropriate measures to take at the next meeting it schedules. The
Director General of the Ministry of Tourism (MoT) stated that a formal complaint from the parents needs to be filed before an investigation of the case could be initiated and claimed that the MoT could close the resort if it is found to violate Law 2000/220 which prohibits discrimination against individuals with disabilities. The Lebanese Association for the Rights of the Disabled (an NGO) requested lawyers to send a warning to the resort and declared that it might decide to sue the resort for violation of the spirit and content of Law 2000/220. Two other similar incidents subsequently occurred at two other different resorts (Miramar and Riviera) (Moussa Charafeddine, personal e-mail communication, August 22, 2004), which adds up to three instances of discrimination and violation of rights that were reported and given media coverage within a two-month period. Needless to say, one could assume that countless similar incidents must occur frequently, although they may neither be reported nor catch the public eye.

All participants in this study agreed that they noticed some improvement in societal attitude towards their children with Down syndrome during the last few years. However, several of them reported a few instances of (a) adults avoiding proximity or contact with their children with DS, (b) parents discouraging their offspring from interacting with them, or (c) parents giving their offspring priority to use play equipment in the playground, thus ignoring the child with DS patiently waiting for a turn. The participants were visibly upset while recounting these incidents to me. Most of them confronted the offending adults to express their discontent and to advocate for their children’s rights. One mother remarked: “They need to learn. I’ve been doing a lot of lecturing!”

The above examples of the general moral and cultural climate serve as reminders that laws are necessary, but not sufficient conditions to change the prevailing system. It takes people to change the system. The advocacy groups that fought long and hard to have Law 2000/220 enacted cannot rest on their laurels yet. They need to make stakeholders (especially self advocates and parents), and the general population, aware of their newly-acquired rights. They also need to enable and equip them to participate in decisions affecting their lives and well being, and to mobilize them to work on broadening their choices. Thus examining the stakeholders’ perspective is a crucial first step in the process of involving them in developing viable, culturally-sensitive systems of service and support that are not wasteful of human potential. Listening to stakeholders and analyzing their input will undoubtedly highlight issues and agenda-setting empirical materials for policy options. It also places them at the center of developing strategies that meet their challenges.

**Summary of Study’s Context**

Finally, just in case the above description of the context does not conjure up a clear image of Lebanon’s complexity and its plight, perhaps the following “prophetic” passage written by Lebanon’s own internationally renowned philosopher and poet, Gibran Khalil Gibran, could bring it into focus. It was quoted by Robert Fisk (2002) in his highly acclaimed book on the civil war in Lebanon:

> Finally, just in case the above description of the context does not conjure up a clear image of Lebanon’s complexity and its plight, perhaps the following “prophetic” passage written by Lebanon’s own internationally renowned philosopher and poet, Gibran Khalil Gibran, could bring it into focus. It was quoted by Robert Fisk (2002) in his highly acclaimed book on the civil war in Lebanon:
After this description of the research study’s setting and the atmosphere that pervades it, an overview of the study’s purpose, questions, definition of terms, rationale, and significance are provided in the following section.

**Research Study’s Purpose, Questions, and Rationale**

**Purpose**

The purpose of this qualitative study was to explore critical factors that surround urban Lebanese mothers’ quest for education and related services for their children with Down syndrome (DS). The intent was to document their experience, to identify key issues, and to develop a conceptual ordering of the phenomenon of educating children with DS in Lebanon that provides a holistic understanding of their mothers’ perspective (i.e., their experience and their views about it). This inductively derived conceptualization, obtained through an analysis process, whereby the
researcher attempts to approximate the perspective of these mothers though the amalgamation of their collective experience and outlook, thus crystallizing the interpretive understanding of their input. This conceptualization could point to issues that need to be explored in further research studies to gain a better understanding of the phenomenon. It could also inform program, as well as, policy development. In addition, it could provide insight into the mothers’ needs as well as their areas of strength that could be used to empower them to advocate for their children and to become active change agents. This exploratory study was also conducted for the following seven reasons:

1. To document the views of Lebanese mothers of children with DS, consolidate their input, and thus initiate the process of involving them as equal partners in building a system of special education and related services that is responsive to their needs and to the needs of their children.

2. To describe the status of special education and related services for children with DS in particular, and for children with mental disabilities in general, by interviewing consumers of these services. In other words, to paint a picture of the present situation from the mothers’ perspective.

3. To profile the views, concerns, needs, and wishes of Lebanese mothers across several critical areas in the provision of special education and related services. Areas to be covered by the interviews will include: Curriculum, placement, support services, their involvement in their child’s education, their need for information, and their present and future areas of concern.

4. To explore Lebanese mothers’ views about DS.

5. To explore Lebanese mothers’ awareness of their children’s rights.

6. To explore Lebanese mothers’ awareness of internationally recognized good practices in the field of special education (e.g., inclusion) and obtain their opinion about the applicability of these practices to their children.

7. To compare Lebanese mothers’ perspective to that of parents from other countries as reported in the research literature.

**Research Questions**

The study will use minimally-structured, open-ended, face to face qualitative interviews to explore the following central question: “**How do urban Lebanese mothers of children with DS obtain education and related services for their children?**” in order to develop a conceptual ordering of the dynamics of this process that explains their experience. Information will be gathered to answer the following sub-questions:
1. What do mothers of children with Down syndrome think of their children’s condition and potential? What are mothers’ beliefs, feelings, attitudes about DS and its impact on one's life?

2. What are mothers’ dreams for their children? What do they think is important for their children to learn?

3. What are mothers' concerns about present and future issues regarding their children?

4. What do mothers believe their children’s rights to be?

5. What is their experience with obtaining education and related services for their children? What factors helped in obtaining services? What factors hindered the process of obtaining services? What do they recommend to facilitate the process?

6. What type of services do the children get? What do mothers think about these services?

7. What other services, if any, do mothers think their children should get?

8. In an ideal world, how would they describe appropriate education for their children? What goals, curriculum, professional services, support, service delivery options, settings, outcomes, etc. would that entail?

9. How aware are Lebanese mothers of internationally recognized good practices in the field of special education (e.g., inclusion) and what is their opinion about the applicability of these practices to their children?

10. What types of support services, if any, do mothers receive? How satisfied are they with these services? If they do not receive any support services, are these services desired?

11. In what ways, if any, do mothers participate in their children's education and in what ways would they like to participate? How involved do they think they should be in their child’s education?

12. What types of information do they consider important for them to receive? What is their preferred format for receiving that information?

13. What demographic, family, mother, and child characteristics are associated with the different views, concerns, needs, and wishes expressed by mothers on the items above?

14. How do Lebanese mothers' views, concerns, needs, and wishes compare with those of parents from other countries, as reported in the current research literature?
Definition of Terms

In order to promote a clear understanding of the meaning of key terms used in this research study, their definitions are presented below.

**Down syndrome (DS)**15. This genetic condition is named after Dr. John Langdon Down, a British physician who was the first person to identify it in 1866. Down syndrome occurs when an individual has three, instead of two, copies of the 21st chromosome (hence its alternate name, trisomy 21). This additional genetic material changes the course of development and produces over 50 characteristics associated with the condition. Every person with DS is a unique individual, who may exhibit these characteristics to different degrees or not at all. However, all people with DS experience mild to moderate cognitive disability. Common physical traits of DS include: low muscle tone, small stature, an upward slant to the eyes with folds of skin at the inner corners (epicanthal folds), and short broad hands with a single deep crease across the center of the palm. People with DS have an increased risk for certain medical conditions such as congenital heart defects, gastrointestinal tract problems, childhood leukemia, thyroid conditions, atlantoaxial instability (misalignment of the top two vertebrae of the neck), respiratory, visual and hearing problems, speech difficulties, and Alzheimer’s disease. Many of these conditions are treatable. Therefore people with DS generally lead healthy lives. A diagnosis of DS is confirmed by the results of a chromosome test (karyotype) that could be administered shortly after birth.

**Education.** The definition of the term “education” used in this study is inspired by and adapted from the definition of Free Appropriate Public Education (FAPE) provided by IDEA (Public Law 108-446, Title I, Part A, Section 602[9], 2004) and its accompanying regulations (34 CFR, §300.17, 2006):

The term “free appropriate public education” means special education and related services that—
(A) have been provided at public expense, under public supervision and direction, and without charge;
(B) meet the standards of the State educational agency;
(C) include an appropriate preschool, elementary school, or secondary school education in the State involved; and
(D) are provided in conformity with the individualized education program required under section 614(d). (IDEA, 2004=Public Law 108-446, Title I, Part A, Section 602[9])

Since the “free,” “public expense,” “public supervision and direction,” and “standards of the State educational agency” components of that definition do not apply to the Lebanese context, appropriate education for the purposes of this study will refer to special education and related services as defined below:

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15 - The definition of Down syndrome was integrated from a variety of sources including the NDSS website; NICHCY (2004), and Lyon (1975).
**Special education.** For the purposes of this study, the term “special education” is defined as programs that go beyond mere accommodation or “care.” “Special education” in this study refers to “specially designed instruction . . . to meet the unique needs of a child with a disability” (IDEA=Public Law 108-446, Title I, Part A, Section 602 (29), 2004; 34 CFR, §300.39, 2006). “Specially designed instruction” means:

> . . . adapting, as appropriate to the needs of . . . [a child with a disability] the content, methodology, or delivery of instruction—
> (i) To address the unique needs of the child that result from the child’s disability; and
> (ii) To ensure access of the child to the general curriculum, so that the child can meet the educational standards within the jurisdiction of the public agency that apply to all children. (34 CFR, §300.39 (3), 2006)

The term special education, as used in this study, includes instructional programs that improve academic, communication, physical and motor fitness, daily living, adaptive, social, travel, vocational, or any other skills needed to promote the development of the child’s potential for independent living, as well as, for dignified meaningful participation and employment in the community. Specially designed instruction could be conducted in the classroom, in the home, in hospitals, or in other community settings.

**Related services.** The definition of related services used in this study is also adapted from IDEA (Public Law 108-446, Title I, Part A, Section 602(26), 2004) and its accompanying regulations (34 CFR, §300.34, 2006). For the purposes of this study, “related services” refers to all services that may be required to assist a child with Down syndrome to benefit from special education. It encompasses diagnostic and evaluative medical services, early identification, early intervention, developmental, corrective, and other supportive services. Specifically, these services include:

> . . . speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, school nurse services designed to enable a child with a disability to receive a free appropriate public education as described in the individualized education program of the child, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services, except that such medical services shall be for diagnostic and evaluation purposes only . . . .

> . . . The term does not include a medical device that is surgically implanted, or the replacement of such device. (Public Law 108-446, Title I, Part A, Section 602[26], 2004)

The IDEA Regulations (34 CFR, §300.34, 2006) also include parent counseling and training as a related service and define it as:
Important note. It is important to mention that the definitions of education, special education, and related services presented above are what these terms are generally understood to refer to within the context of the educational system in the USA. These definitions were not shared with the study’s participants in any way. They are included here because they definitely colored my processing of participants’ description of their children’s programs, and thus shaped the study’s findings as well as influenced their interpretation.

Urban. Webster’s Online Dictionary (www.websters-online-dictionary.org) defines urban as: “A name that signifies or is derived from: ‘a city dweller’” and as an “Adjective: (1) Relating to or concerned with a city or densely populated area . . . [or] (2) Located in or characteristic of a city or city life.” Since what is considered to be a city depends on country size and demographic characteristics, for the purposes of this study the adjective urban will be used to refer to residents of greater Beirut.

Rationale for Choice of Population

The rationale for focusing on the perspective of urban Lebanese mothers to explore the phenomenon of educating children with Down syndrome is presented below.

Why mothers? Although caring and responsibility are not gender issues, the mother has always been considered the essential half of the partnership when it comes to child-rearing. This is especially true in traditional societies with patriarchal family structures. In her book, *The Tending Instinct*, Shelley Taylor (2002) a psychologist at UCLA who advanced the “tend and befriend” theory, compares human tending to the layers of an onion with the core layer representing the mother. The next layer of constant caregivers includes the father. The third layer consists of family and close friends. The fourth layer represents the neighborhood and larger community. She carries the metaphor to its logical conclusion by specifying that each layer serves as the protector for those that lie closer to the core.

A mother is usually her baby’s primary lifeline and his best advocate. Mothers are genetically programmed to look after their children and care about them. Some brain hormones have been found to control the fearless protection, nurturing, and mothering responses (Epps, 2004; Gammie, et al, 2004; Lawrence, 1994; Love, 1995). Stern and Stern (1998) describe the “maternal instinct” as follows:
Mothers play a unique role in their child’s development. This process begins soon after birth, when mother and child are synchronized physically and mentally as demonstrated by the automatic regulation of breast milk flow to fit the infant’s feeding schedule and the mother’s hyper-alertness to her child’s cries of distress (Epps, 2004; Herzog, 2004). As the children grow physically and mentally, their mothers’ intuitive understanding of their behavior enables them to support and nurture their development. Compelling evidence on the crucial role maternal responsiveness plays in the cognitive development of their children was provided by Bornstein and his colleagues (Bornstein, 1989; Bornstein & Tamis-LeMonda, 1989) who conducted a series of longitudinal studies and reported in one analysis that maternal responsiveness to 4-month-old infants was predictive of the children’s cognitive competence at age 4 years, even after maternal noncontingent stimulation and measures of infant information processing were factored out.

The mothers’ attunement to their children’s needs, their ability to read them and to see the world from their perspective, their unconditional love for them, their commitment to their well-being, the relatively larger amount of time they tend to spend with them, and briefly the central role they play in their development, make them the ideal potential participants in a study focusing on educating children with DS.

Another reason for focusing on mothers’ perspective is a technical one. Since the 1970s, women interviewers have been encouraged to interview other women from the “empathic standpoint of gender” (Warren, 2002, p. 95). Although a woman interviewing women may alleviate “feminist interviewing” proponents’ concerns about gender dominance issues (DeVault, 1986, as cited on page 95 of Warren, 2002), it may introduce other issues relating to differences in educational, socio-economic, religious, political, and marital status between interviewer and interviewee that could influence interviewee’s willingness to fully cooperate (Hertz, 1996). Rapport and trust-enhancing interview strategies, such as an accepting non-judgmental attitude and Rogerian mirroring, could be used to overcome interviewee reluctance to cooperate in those cases, but might seem deceitful and therefore ethically problematic (Luff, 1999, p. 698). What is more important in Lebanon are two factors (1) access to women participants from conservative religious communities and (2) interviewer’s relationship to the decision-making structure that provides and administers educational services. Being a woman puts me at an advantage because it gives me access to the perspectives of mothers from all religious and socio-economic strata, a privilege that might not be available to male researchers in that context. In addition, the fact that I have been affiliated with several disability advocacy groups since 1998, and that I am perceived to be working alongside parents to promote the development of equitable educational opportunities for children with disabilities, might overcome potential participants’ reluctance to cooperate for fear of reprisals. In addition, it could even elicit more candid accounts of the mothers’ experience and views on the subject.
Why Down syndrome? This single etiological group of children was chosen in order to eliminate the possibility that the type of disability could be a confounding factor in formulating mothers’ views about appropriate educational programs. Children with Down syndrome were also chosen for the following reasons:

1. **Incidence:** Down syndrome is the most common chromosomal condition associated with intellectual disability. Its incidence is about 1 in every 800 to 1000 live births (NICHCY, 2004).

2. **Identification:** Children with DS are readily identifiable at birth and there is little ambiguity with respect to their membership in the group (Gibson, 1978; NICHCY, 2004).

3. **Level of functioning:** Although, just as in the general population, there is a wide variation in cognitive abilities, behavior, and developmental progress in individuals with Down syndrome, the majority function within the mild to moderate range of mental retardation (NICHCY, 2004).

4. **Potential:** Recent research suggests that children with DS generally have better social abilities than other children with cognitive disabilities (Kasari, Mundy, Yirmiya, & Sigman, 1990; Legersten & Bowman, 1989). Indeed, their social abilities may actually compensate for their cognitive difficulties (Kasari & Hodapp, 1996; Pitcairn & Wishart, 1994), thus indicating a higher achievement potential.

5. **Access to participants and informants:** Because I have been on the executive board of the Lebanese Down Syndrome Association, almost since its inception in 1998, and have served as its volunteer educational consultant during that period, I have established a level of credibility and rapport with its leadership that will facilitate access to participants and informants needed and thus will smooth the process of conducting the research study.

Why urban? Because of the relatively small sample size and the complexity of Lebanese society’s fabric, only urban mothers of children with DS were chosen to participate in this study. Their memberships in unique combinations of social, economic, political, and sectarian communities were expected to be associated with a wide variety of viewpoints and approaches to educating their children with DS, thus making it difficult to make sense of their collective experience without considerably expanding the study’s sample size to capture as many exceptions as possible to the emerging patterns of empirical materials. In addition, although sample representativeness is not an issue in this study, urban mothers’ perspectives is more likely to reflect the typical dynamics of educating children with DS in Lebanon because the majority of the Lebanese population is concentrated around urban centers, and about half of the population lives in greater Beirut. Thus focusing on urban mothers’ perspective not only facilitated the interpretability, but also enhanced the usefulness of the study’s findings for policy planning and future research and was instrumental in starting to fill the large information gap on disability issues in Lebanon. Finally, only urban mothers were selected for the sake of expediency, since I do not have access to a car in Lebanon and would prefer to avoid complicated transportation logistics (and associated expenses) to rural areas.
Need for and Significance of the Study.

The special education literature advocates parent involvement in the education of children with disabilities (e.g., McAfee & Vergason, 1979). It substantiates the vital role productive parent-professional partnerships play in the development of children with disabilities (Welch & Odum, 1981). As a matter of fact in some countries (e.g., the USA) participation of parents in the special education process is not merely considered good educational practice, but constitutes a right that is protected, respected, and achieved in accordance with standards established and regulated by legislation and litigation (Turnbull & Turnbull, 1985). In Lebanon however, parents generally believe that education is the responsibility of the schools. They usually rely on professionals to take care of any problems that arise and are actually discouraged from seeking involvement. Parents of children with disabilities, whose children with special needs are generally automatically referred to special programs run by NGOs because most schools are currently neither equipped nor willing to serve them, are not even considered as part of the picture. Professionals generally act condescendingly towards them and customarily view them as having very little to offer in their children’s habilitation process. The discounting of their input, with the consequent loss of their potential contribution, and the marginalization of their role jeopardize the quality of intervention programs and place parents of children with disabilities in a dangerous situation. On the one hand, in addition to the strain and difficulties commonly experienced by families of children with disabilities (Turnbull & Turnbull, 1997), Lebanese parents of children with disabilities are faced with popular misconceptions fed by lack of accurate information about disabilities. The resulting stigmatization and mistreatment sometimes drive them to either hide the disability or to perseverate in seeking cures through medical, religious, or even superstitious means. On the other hand the current lack of effective intervention programs reinforces their worst fears by widening the gap between their children’s level of functioning and that of their children’s typical peers.

Because of the magnitude of the problem, in light of internationally recognized good practice, and in view of recent positive developments in the field of special education in Lebanon, it is both timely and imperative to listen to the views and needs of parents, especially mothers, of children with disabilities in order to give credence to and endorse the critical role that they could play in the planning and implementation of culturally appropriate programs to meet their needs and those of their children. This study is the first systematic attempt to listen to Lebanese mothers of children with Down syndrome and to document their views and needs. This effort constitutes a small first step in the process of involving them as equal partners and empowering them to advocate for their children.

Besides its potential contribution to highlighting and valuing the role of Lebanese mothers in the education of their children with DS, this study will yield much-needed information to understand the critical factors in the process mothers go through to locate education and related services for their children with DS in Lebanon, thus depicting the current status of the field from their perspective, as well as their views of their experience, and their needs. Because of the dearth of
information on this topic, these valuable empirically derived materials, the insights gained, and
the conceptualization of the dynamics of the process of securing education and related services
for children with DS will be useful for research and for planning purposes to improve delivery of
services. The study’s findings could also constitute a point of departure for developing a
comprehensive supportive, capacity building program for parents and other stakeholders as well
as an advocacy strategy aimed at promoting full participation of individuals with disabilities in
the educational system and all aspects of Lebanese society, thus advancing the realization of
their long-awaited full citizenship rights. In addition, Cross-cultural comparisons of this study’s
findings with those obtained in other countries will undoubtedly generate useful inferences about
the phenomena of parenting and educating children with disabilities.

Summary and Transition

After stating the problem, this chapter described the study’s setting, then provided an overview of
the investigation’s purpose, research questions, rationale, and significance. Chapter 2 reviews the
professional and research literature on the perspective of parents of children with disabilities and
the role they play in educating them, then discusses the extant literature’s limitations. Chapter 3
specifies the study’s strategy of inquiry, theoretical lens, and perspective, as well as the
procedures for selecting informants and participants, collecting, recording, managing, analyzing,
and safeguarding the trustworthiness of its empirical materials. Finally, the study’s empirical
findings are presented in Chapter 4 and discussed in Chapter 5.
CHAPTER 2

REVIEW OF THE LITERATURE

A review of the professional and research literature about the perspective of parents of children with disabilities and the role they play in educating them was conducted while planning the research study. It revealed a considerable increase in the number of publications examining the experiences and needs of families of persons with disabilities within the last two decades. An overwhelming majority of the publications dealt with American, western European, or Australian settings. Some publications focused on the viewpoints of Mexican, Puerto-Rican, Chinese, and Korean parents of children with disabilities residing in the USA or Canada. One study (Kabinde & Ngwenya, 1995) interviewed black parents of children with disabilities in South Africa. A few studies tangentially addressed families of children with disabilities in developing countries, e.g., Jordan (Yousef & Hadidi, 1992) and Turkey (Akkok, 1994). Seven publications dealing with education or disability issues in Lebanon were found. However, only two of the latter, (Bahous & Nabhani, 2008; Wehbi, 2006), listed below, broadly addressed special education.


Rima Bahous and Mona Nabhani (2008), Lebanese American University, investigated socioeconomic, political, and inclusion/exclusion issues in three schools in Beirut (two leading private schools and one public school). They stated that inclusion “extends beyond mainstreaming special needs students to developing schools that are responsive to diverse learners” (p. 131). Then they mentioned that:

In the revised National Curriculum in 1995 (NCERD, 1995), inclusion is theoretically encouraged at all levels; however in practice there are many problems. Many schools still do not cater for students with special needs. Some schools state this clearly while others create procedures that weed out students with learning or behavioral problems . . . . On the other hand, some non-governmental organizations (NGOs) are working to make students’ inclusion easier. (p. 131)

They found that, in the case of the two leading private schools they studied, remedial classes were provided and teacher development as well as teacher accountability were emphasized. However, there were examples of exclusion of students from lower socio-economic classes and of students who had lower ability levels or insufficient command of the foreign language of instruction. The public school they studied catered to the lower socio-economic classes, did not provide remedial classes, and exhibited a “lack of administrative and representative social justice” (p. 138).

Samantha Wehbi’s article reported on the findings of Phase I of the National Inclusion Project (NIP), which was described in Chapter 1. The NIP was initiated by a consortium of four NGOs and funded by the World Bank. The aim of Phase I was to examine available information, policies, legislation, and existing inclusion programs in education and employment in order to identify the main stakeholders and issues. Two common themes were generated by the study’s findings: (1) a perceived need for raising awareness about disability issues and (2) a perceived lack of adequate teacher training. Wehbi (2006, p. 337) also pointed out that the perspective of children with disabilities and that of their families were absent, eclipsed by that of educators or other professionals.

In view of the fact that no publications relating to the problem investigated in this study were found, a general review of the literature about the topic was conducted. As is the case in qualitative studies, because it is impossible to predict beforehand what problems and theoretical concepts will emerge during fieldwork, literature that relates to this study’s empirical findings will be presented in Chapter 5: Discussion. This chapter provides an overview of the issues, trends, and limitations of the professional and research literature relating to the topic of mothers’ views and involvement in the education of their children with intellectual disabilities. It focuses on the following six issues:
1. Impact of disability on families
2. Views of disability
3. Evolution of parents’ role
4. Evolution of intervention programs
5. Cross-cultural perspective on intervention programs

**Impact of Disability on Families**

Mental retardation has been described as probably the most alarming diagnosis a parent can receive (Fewell, 1986) and as a tragedy comparable to death (Davis, 1987; Nicholas & Lewin, 1987). Early research on the impact of the birth of children with disabilities on families (usually mothers) adopted a pathological view of maternal adjustment and presented a grim picture of stress, burden, depression, psychological dysfunction, marital discord, and social isolation (Shapiro, 1983).

For many years, the professional literature was dominated by theoretical constructs such as (1) “chronic sorrow” (Copley & Bodensteiner, 1987; Phillips, 1991) which implied an unavoidable, persistent state of grief and mourning, and (2) “stage theories” which portrayed maternal reactions to a child with mental retardation as an inevitable predictable progression from the pathological responses of shock, denial, guilt, blame, anger, and depression to potential acceptance and resolution (Allen & Affleck, 1985; Blacher, 1984b; Fortier & Wanlass, 1984; Jackson, 1985). However, empirical investigations of these constructs made researchers question whether they are merely examples of consensual thinking rather than reality-based paradigms (Workman & Silver, 1989). Nevertheless, despite their shortcomings, these theoretical constructs are still being propagated in the literature.

A key theory that influenced the professional literature on maternal reaction to disability was advanced by Bronfenbrenner (1979) who placed parenting behavior within its ecological context. According to his model maternal adaptation could only be understood in the context of the ecological influences within and outside the family system. He postulated four levels of concentric structures whose interaction strongly affect parent/child relationship: (1) microsystems (e.g., family, peer group, school), (2) mesosystems (systems created by the interaction of microsystems, such as family and school), (3) exosystems (environments that may exercise an indirect effect, such as social support networks), and (4) macrosystems (e.g., legal systems, public policy-making institutions, society at large). Other key theoretical formulation of family adjustment that influenced the professional literature was the Double ABCX model (McCubbin & McCubbin, 1987) which is derived from Hill’s (1958) classic ABCX model. This model describes family crisis (X) as an interactive outcome of three factors: (A) an initial stressor, (B) family resources for dealing with crises, and (C) how the family defines the stressor.
It acknowledges that the effect of stressors on family members are dependent on mediating variables such as family resources including personal resources of individual family members and those of the family unit, social support, cognitive appraisal of the stressor by individual family members, and the family’s general worldview (Patterson, 1993).

In addition to changes in the theoretical research models, parents expressed concern that the professional literature inadequately represented their experience with their children with disabilities. Turnbull, Patterson, Behr, Murphy, Marquis, and Blue-Banning (1993) raised several issues regarding the ethics and accuracy of research on families. Summers, Behr, and Turnbull (1989) had analyzed anecdotal reports from parents that pointed to positive aspects of having children with disabilities, including personal growth, greater compassion and tolerance, and coping strength. In addition, Ferguson and Ash (1989), who reviewed published narratives written by parents and persons with disabilities, found that the disability itself does not overwhelm all other considerations and concluded that:

> The most important thing that happens when a child with disabilities is born is that a child is born. The most important thing that happens when a couple becomes parents of a child with disabilities is that a couple becomes parents. (Ferguson & Ash, 1989, p. 108)

Later research that explored complex personal, social, and ecological variables that mediate and moderate the impact of disability on the family, emphasized the interactive and developmental nature of maternal adjustment, and situated the mother’s adaptation within the context of a multitude of intrapersonal and external factors. In their careful review of the literature, Shapiro, Blacher, & Lopez (1998) arrived at the following conclusions:

> . . . although we need to correct a pathological view of mothers of children with disabilities, significant differences do exist, at least on some dimensions, between mothers of children with and without retardation, as well as between mothers and fathers of children with mental retardation. The evidence suggests that mothers continue to be more strongly affected than fathers by the care giving requirements associated with a child with disabilities, although there is little reason to believe that their greater sense of stress and burden is reflected in clinically significant maladaptation. Further, it is not completely clear whether higher levels of physical or emotional symptomatology are related to the presence of a child with mental retardation, to a host of mediating variables, or to differences between men and women in the larger population unrelated to child disability. Similarly, though a growing body of information finds few differences on many adaptive outcome measures between mothers of children with and without disabilities, usually differences that are found favor mothers of children with normal development. This is not to say that families of children with disabilities and retardation are dysfunctional or poorly adaptive, but simply that they are required to respond to more challenges in the process of raising their child with disabilities. . . .

What we are beginning to realize is that maternal and family reaction to disability, and to mental retardation in particular, is highly variable, so that it is difficult and inaccurate to talk about "families of children with retardation" in a general sense. (Shapiro, Blacher, & Lopez, 1998, p. 625)
Their conclusions were echoed by Ferguson (2001) who stated that:

Family research has found its place within the emerging perspective of disability studies by increasingly accepting the assumption that it is not a specific set of parental reactions to disability that is inevitable but the influence of social contexts in shaping those reactions. (Ferguson, 2001, p. 375)

Ferguson (2002) later extended that conclusion and argued that professional explorations of family reactions to a child with a disability must be participatory (“a shared activity of meaning-making”) and must be steeped into the sociohistorical and cultural context.

It is perhaps commonplace now to argue that a family’s reactions to having a child with a disability are inescapably embedded within a sociohistorical context. As with all human endeavor, a family’s interpretation of the meaning of disability cannot help but reflect to some degree the larger context of social attitudes and historical realities within which that interpretation emerges. What is implicit within this argument, but perhaps less commonly acknowledged, is that our professional explorations of those family reactions must be equally embedded in the hidden assumptions and cultural expectations of a specific era. As family researchers, we try to interpret the interpretation of families, and it is this shared activity of “meaning-making” that ties us to our time and place. (Ferguson, 2002, p. 124)

**Views of Disability**

Although permanent impairments of body and mind, that may limit full functioning, exist everywhere in the world, their significance depends on more than their physiological nature and is shaped by the contextual circumstances in which they are situated. The professional literature reviewed suggests that the concept of disability does not have a universal character. The common meanings associated with disability emerge out of specific social and cultural contexts and vary with time.

In some cultures and languages there is no term for “disability”, and social “difference” is categorized in many different ways depending on how it affects the pursuit of what is valued by that culture. One of the most detailed recent anthropological evidence on the diversity of cultural attitudes to disability is provided in *Disability and Culture*, edited by Ingstadt and Whyte (1995). In their attempt to relate disability to fundamental assumptions about humanity (value as a human being) and personhood (social position and possibilities) they studied conceptions of social difference in several traditional cultures in developing countries. They found that there is astonishing cultural variation in what makes or undermines “personhood.” They reported that among the Maasai in Kenya, “people’s physical or mental capacities are not culturally constructed as differences having implications for a person’s fulfillment in life” (p. 70). However, for the Tuareg in West Africa, social participation is affected by a number of factors:
“old age and immaturity (making one physically dependent), illegitimate birth (making one socially anomalous), and ugliness (rendering it difficult to marry)” (p. 6). In many traditional societies, such as the Punan Bah (Borneo), the key disabling condition is failure to have children, since parenthood is the fundamental indicator of adult status (p. 50).

There are those who argue, like Scheer and Groce (1988) that small traditional societies provide more forms of support and more opportunities for social participation for people with impairments, in contrast to the situation in more complex, industrial societies. Since the predominant approach to people with impairments in such societies, mainly in the western hemisphere, has historically been to isolate them from the general population, most common beliefs about disability are derived from secondary sources rather than firsthand experience. The most pervasive, and yet the least recognized source of such beliefs is the cultural context, that could be described as the “stew of images and stereotypes about disability that inevitably simmers on the back burner of everyone’s consciousness as we make our way through life” (Ferguson, Ferguson, & Taylor, 1992, p. 8). Such beliefs originate from hearsay, folklore, fairy tales, literature, arts, films, mass media, and other suppliers of cultural imagery. The second-hand nature of these beliefs and their focus on global rather than individual “particularistic” views tend to perpetuates negative images and stereotypes of disability. According to Zola (1992, p. 244) “one of the dilemmas that people with disabilities confront is that they are seen globally but not particularistically.”

Within the last two decades, social scientists, activists, and advocates have argued that the concept of disability is as much a socially and politically constructed phenomenon as it is the presence of any particular physical, psychological, biochemical, or physiological difference (e.g., Zola, 1992; Linton, 1998a, 1998b). For instance, the Disabled People International (DPI) Europe position statement (DPI, 1994), distinguishes “impairment”, which refers to a medically classified condition, from “disability”, which is a generic term used to denote the social disadvantage experienced by people with an impairment. Disability, Human Rights and Society, a series of books edited by Len Barton, University of London, clarifies this distinction further and emphasizes its political ramifications. It situates disability within an equal opportunities framework, defines it “as a form of oppression and identifies the ways in which disabled people are marginalized, restricted, and experience discrimination.” Authors of the series are united in the belief that: “The fundamental issue is not one of an individual’s inabilities or limitations, but rather a hostile and unadaptive society.” They also recognize that efforts to promote needed changes in order to provide opportunities for people with disabilities “cannot pretend to be apolitical” and that they necessitate collaboration with other marginalized groups (race, gender, age).

16 - Disability, Human Rights and Society is a series of eleven books edited by Len Barton, Institute of Education, University of London, published between 1998 and 2003. The quotes were excerpted from the description of the series which appears on page ii of each volume.
Evolution of Parents’ Role

Historically, professionals have ascribed a variety of roles to parents and families of children with disabilities. Some of these roles were unfavorable and unjustified, some were dictated by necessity, and some were spontaneously and eagerly initiated and carried out by them. Philip Ferguson (1994, 2001, 2002) and Ann P. Turnbull with her husband H. Rutherford Turnbull III (1997, 2001) who are parents of children with disabilities, as well as professionals in the field, have provided insightful historical retrospectives of the different roles professionals attributed to parents, mainly in the USA and generally in the western hemisphere. The roles identified in their separate accounts were combined into the following eight major types:

1. Parents as the source of their child’s problems
2. Parents as organization members
3. Parents as service developers
4. Parents as recipients of professionals’ decisions
5. Parents as teachers
6. Parents as political advocates
7. Parents as educational decision makers
8. Parents as collaborators.

While reading the brief discussion of these roles presented below, it is important to keep in mind—as Turnbull and Turnbull (1997, pp. 4 & 12) suggested—the following five points: (1) no single role characterized all parents; (2) some parents have played all or most roles; (3) the roles identified overlap; (4) the roles do not represent discrete historical periods, although a broad chronological progression is discernible, and (5) all eight roles are still evident nowadays, although according to Turnbull and Turnbull (2001) the predominant contemporary role for parents is that of collaborators.

Parents as the Source of Their Child’s Problems

Throughout the nineteenth century and early twentieth century, the blame for disabilities was placed on parents. Asylums, reform, and residential schools were created to preserve children with disabilities from the influence of their parents and to allow professionals to assume the parental role within the walls of their facilities (Ferguson, 1994). The professional claims of specialized knowledge, their promises of cure or amelioration, and the fact that these programs were subsidized by the government, thus providing much needed financial relief for many families, promoted a rapid increase in institutionalization (Ferguson, 2001). Early in the
twentieth century during the eugenics movement (1880-1930), sterilization was proposed as a “surgical solution” (Reilly, 1991) for reducing the incidence of cognitive disabilities and selective breeding was encouraged to improve the human race (Ferguson, 1994; Turnbull & Turnbull, 1997).

Parents as Organization Members

Because many parents and other family members were not satisfied with the public and professional responses to their children’s educational and other needs, they sought emotional support from others with similar circumstances and began to organize at the local level in the 1930s and at the national level in the late 1940s and 1950s. The National Association of Parents and Friends of Mentally Retarded Children, which after several name changes is currently known as The Arc, was established in 1950 by 42 parents and other concerned individuals from 13 states (Turnbull & Turnbull, 1997). Other disability-specific parent associations (e.g., the National Association for Down Syndrome, founded in 1961) were organized later. Although these parent organizations advocated for and were instrumental in developing better service delivery options, not all parents considered joining them as helpful or even necessary, which might account for the fact that their members were generally predominantly white middle class parents (Turnbull & Turnbull, 1997, 2001).

Parents as Service Developers

In the 1950s and 1960s, because their children were generally excluded from public schools, parents and the organizations they created concentrated on developing services for children and adults with moderate and severe disabilities. They created public awareness of their children’s needs, used community facilities (public, private, and church buildings) to operate a variety of needed programs, solicited financial support from charitable organizations or engaged in other fund-raising activities, and advocated for the programs they started to be taken over by appropriate agencies. Samuel A. Kirk, a distinguished special educator, described the contribution of parent organizations in developing special education services as follows:

> If I were to give credit to one group in this country for the advancements that have been made in the education of exceptional children, I would place the parent organizations and the parent movement in the forefront as the leading force. (Kirk, 1984, p. 41, as quoted in Turnbull & Turnbull, 1997, p. 7)

Parents as Recipients of Professionals’ Decisions

Professionals in the field of special education have long expected parents to delegate decisions about their children’s programs to them and “to comply passively and gratefully” with these
decisions (Turnbull & Turnbull, 1997, p. 7). The following quote from a leading textbook on methods of educating students with disabilities illustrates this attitude:

Should it be judged that special class placement will probably be of most benefit to the child, then placement should be made without delay. Both the child and his parents should be told that the child is being transferred into the special class . . . . The entire program should be explained so the parents will understand what lies ahead for the child and so they can support the efforts of the teachers with the child. (Kolstoe, 1970, p. 42, as quoted in Turnbull & Turnbull, 1997, p. 7)

Some professionals still try to impose program and placement decisions on parents (because they believe they know best) and they often assume an authoritarian approach that intimidates and at times angers parents (Turbiville, Turnbull, Garland, & Lee, 1996).

Parents as Teachers

The parents as teachers approach emerged during the late 1960s and sought to promote positive parental involvement through behavioral training programs. This represented a reversal of the previously predominant assumption that advocated “parentectomy” namely replacing natural parents with professionals and institutional staff, who were alleged to be more competent. Lasch (1977) described the vicious cycle in which parents were caught:

Having first declared parents incompetent to raise their offspring without professional help, social pathologists “gave back” the knowledge they had appropriated—gave it back in a mystifying fashion that rendered parents more helpless than ever, more abject in their dependence on expert opinion. (p. 18)

Parents as Political Advocates

Between 1950 and 1970, because educational services for students with disabilities were inadequate, parent groups became successful political advocates at the local, state, and federal levels and in legislatures, courts, and executive agencies.

Parents as Educational Decision Makers

In 1975, the promulgation of Public Law 94-142, Education for the Handicapped Act, the precursor of the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), granted parents of children with disabilities active decision-making rights.
Parents as Collaborators

Since 1986, when Public Law 99-457 was promulgated, the conceptualization of parents as equal and full partners, or collaborators, with professionals has evolved into the currently prevalent and accepted approach known as family-centered practices. According to Dunst (2002, p. 141), the term family-centered refers to “a particular set of beliefs, principles, values, and practices for supporting and strengthening family capacity to enhance and promote child development and learning.” Dunst & Trivette (1996) distinguish between two essential components of family-centered practices: relational and participatory. The relational component includes practices typically associated with (a) good clinical skills (e.g., active listening, compassion, empathy, nonjudgmental attitude, treating families with respect and dignity) and (b) professional beliefs about and attitudes toward families, especially those pertaining to parenting capabilities and competencies. The participatory component includes practices (a) that are individualized, flexible, and responsive to family concerns and priorities and (b) that provide families with opportunities to be actively involved in informed decisions and choices, family-professional collaboration and partnerships, mobilization of resources and supports to produce optimal child, parent, and family outcomes.

Evolution of Intervention Programs

In the absence of published accounts of intervention programs for children with disabilities in Lebanon, it might be helpful to refer to available conceptualizations of the evolution of such programs in other cultures. This could provide some insight regarding the stage of evolution of special education and related services in the country. Two historical interpretations that trace the origins, development, and interaction of ideologies of intervention programs leading to present thinking in special education in western societies, were provided by Lipsky and Gartner (1997) and by Clough and Corbett (2000).

Lipsky and Gartner (1997) in their review of the US literature traced the evolution of intervention program ideology through three eras:

1. The era of institutions
2. The era of deinstitutionalization
3. The era of community membership.

A more detailed, yet parallel, conceptualization of the evolution of intervention programs’ ideologies in—a different but, similar cultural perspective—the United Kingdom, was proposed by Clough and Corbett (2000). They identified five major perspectives that are neither completely exclusive of each other nor chronologically sequential and then delineated an
insightful conceptual framework for analyzing the evolution of such programs from segregated to inclusive.

1. The psycho-medical legacy (1950s to early 1960s)

“This is understood as the system of broadly medicalized ideas which essentially saw the individual as being somehow in ‘deficit’ and in turn assumed a need for a ‘special’ education for those individuals.” (Clough & Corbett, 2000, p. 8)

2. The sociological response (late 1950s to late 1970s)

“This position broadly represents the critique of the ‘psycho-medical legacy’, and draws attention to a social construction of special educational needs.” (Clough & Corbett, 2000, p. 8)

3. Curricular approaches (late 1960s to late 1980s)

“Such approaches emphasize the role of the curriculum in both meeting—and for some writers, effectively creating—learning difficulties.” (Clough & Corbett, 2000, p. 8)

4. School improvement strategies (late 1970s to late 1990s)

“This movement emphasizes the importance of systemic organization in pursuit of truly comprehensive schooling.” (Clough & Corbett, 2000, p. 8)

5. Disability studies critique (late 1980s to early 2000s)

“These perspectives, often from ‘outside’ education, elaborate an overtly political response to the exclusionary effects of the psycho-medical model.” (Clough & Corbett, 2000, p. 8)

Cross-Cultural Perspective

Although a lot has been published about families of children with mental disabilities, historically most of this writing is in the form of reports or research studies, which examined particular issues and were conducted in specific countries and cultures, mostly American or western European. The declaration by United Nations of 1981 as the International Year of Disabled Persons, followed in 1983 by the declaration of United Nations Decade for Disabled Persons (1983-1992), put disability into a global context and initiated interest in exploring how disability is perceived and dealt with in different societies.

The United Nations’ declaration of 1994 as the International Year of the Family prompted the International League of Societies for Persons with Mental Handicap (ILSMH)\(^\text{17}\) to establish a

\(^{17}\) ILSMH was established in 1962 and had 150 member societies in nearly 100 countries in 1995 (Mittler, 1995, p. iv).
task force in 1992, co-chaired by Helle and Peter Mittler, University of Manchester. This task force comprised one mother and one father from each of the main regions of the world (Africa, Asia, the Arab region, Australasia, Europe, North America, and South America) as well as the chairs of the League’s committees on the family and on brothers and sisters. One of the goals of this task force was to “Clarify variations in the experience of families in different countries and regions, with disabled members at different life stages and with a range of needs arising from profound levels of disability or from behavior which is difficult to manage” (Mittler, 1995, p. vi). The task force members collected 80 family stories which provide some insight into the effect of living and caring for a child with disabilities in different cultural contexts. These were analyzed and included in Helle Mittler’s (1995) *Families speak out: International perspectives on families’ experiences with disability*. This publication includes 18 comments by Lebanese parents on their reactions to the news; the unfair treatment their children receive; their disabled child’s impact on and contribution to family life; available support from extended family and neighbors; differences in coping between fathers, mothers, and siblings; ideas for improving available services, and concerns about the future.

In addition to the above book, six ambitious attempts to present a cross-cultural perspective of special education and related services were identified in the literature.

The first one is a book entitled *Education and disability in cross-cultural perspective* that was published in 1993 as part of a series of reference books on international education. This book, edited by Susan Peters (1993), is a collection of chapters contributed by experts in the field who reside and are active professionals within the educational systems of seven countries. It does not include any information about intervention programs in Lebanon or in other Arab countries.

Another attempt to fill the cross-cultural void in the special education literature was undertaken by Mazurek and Winzer (1994) who in their edited book, *Comparative Studies in Special Education*, offered a general overview and synthesis of developments around the world. They presented case studies contributed by experts in the field who reside and are active professionals within the educational systems of 26 countries. Case studies from two Arab countries (Egypt and the West Bank & Gaza Strip) describing the status of special education, along with major issues and emerging trends, were included in the “limited” and “emerging” systems sections of the book. However, no information about special education in Lebanon was included.

Prompted by their dissatisfaction with much of the existing comparative education literature, Booth and Ainscow (1998) in their book entitled *From Them to Us: An international Study of Inclusion in Education* presented a unique comparative study. They gathered a team of

18 - Case studies from the following seven countries (listed in alphabetical order) were included: China, Hungary, Iran, Japan, Pakistan, UK (England & Wales), and USA.

19 - Case studies from the following 26 countries (listed in alphabetical order) were included: Australia, Brazil, Canada, China, Czechoslovakia, Egypt, Finland, Hong Kong, India, Indonesia, Iran, Israel, Japan, New Zealand, Nigeria, Pakistan, Papua New Guinea, Poland, Russia, Senegal, South Africa, Taiwan, UK (England & Wales), Uruguay, USA, West Bank & Gaza Strip.
researchers from eight countries and asked them to develop case studies that explore the processes of inclusion and exclusion within a school or a group of schools in that country. The study included classroom observation, interviews with students, parents, teachers, school staff and administrators. Their analyses of these case studies revealed interesting differences of perspectives within and between countries. All the case studies included were developed in western countries.

Armstrong and Barton’s (1999) book entitled Disability, Human Rights, and Education: Cross-Cultural Perspectives recognized the importance of an informed cross-cultural understanding of policies and practices in the field of disabilities and focused on how human rights are understood in different countries and their implications for education. Early in the book, Armstrong and Barton expressed their aversion for the traditional portrayal of “the western” as advanced and exemplary in contrast to the depiction of “the rest of the world” as backward and inferior.

Western attitudes, values and practices are far from exemplary in the area of human rights and disability, and there is no room for assuming any society has a preordained prerogative to speak for, about and at other societies defined as “developing” or “Third World” . . . . All societies have much to learn and develop in this matter, not least in terms of generating an open curiosity about different cultures that allows us to listen better, to take notice and to dismantle preconceived ideas about values and practices in different social contexts, including within our own societies. (1999, p. 2)

Contributions from both western and developing countries are included in the book, but no information from Middle Eastern or Arab countries was solicited.

Finally, a two-volume work in the series Inclusive Education: Cross Cultural Perspectives, edited by Barton and Rioux, was published in 2003. In volume I, entitled Spaced out: Policy, difference and the challenge of inclusive education, Felicity Armstrong analyzed the social construction of difference and its relationship with the broader socio-political, cultural context in two settings: England and France. She focused her attention on “spacializing processes and discourses” i.e., the ways in which space is used and the impact of “segregated space” on social relations, identities, and opportunities. Volume II, edited by Julie Allan and entitled Inclusion, participation, and democracy: What is the purpose? is a collection of papers by scholars from western countries on the goals of inclusion, participation, and democracy and how to achieve them.

20 - Case studies from the following eight countries (listed in alphabetical order) were included: Australia, England, Ireland, Netherlands, New Zealand, Norway, Scotland, and USA.

21 - Case studies from the following 14 countries (listed in alphabetical order) were included: Australia, Canada, China, Cyprus, England, France, Greece, Hong Kong, Pakistan and Bangladesh, Romania, Sweden, Trinidad and Tobago, USA, and Zimbabwe
Methodological Limitations

Until recently, the research literature on family issues relating to disability has used predominantly quantitative methodologies. Data collection procedures such as standardized instruments, researcher-developed rating scales, questionnaires, surveys, structured interviews, and observation schedules, all of which reflect the values, beliefs, and biases associated with the positivist paradigm, were used in most studies (Patching & Watson, 1993). The positivist research paradigm is also associated with the deficit approach to family support and to the lack of recognition of their rights, needs, views, and values. According to Biklen (1988), this approach places families at risk of “social processing and control,” since they become targets for treatment and victims of the medical model which emphasizes diagnosis, classification, labeling, placement, and prescription. In addition, reliance on this research paradigm implies that power and decision-making are primarily vested in the researcher, and therefore contradicts state of the art democratic and rights-based approaches. As early as the late eighties, several professionals had appealed for a higher level of sophistication in selecting a research paradigm for this area (e.g., Biklen, 1988; Skrtic, 1991).

Perhaps as a consequence of the preponderance of quantitative studies, two key perspectives have received less attention in the literature, until recently: (1) the perspective of families (direct accounts by parents, siblings, and other family members, i.e. family voice rather than professional voice) and (2) a more global cross-cultural perspective that does not revolve around western settings.

Conclusion of Literature Review

Dealing with the consequences of disability depends on a society’s response to disabling conditions. According to Peters (1993, p. 3): “Both loss of productivity and quality of life are mediated by societal conditions, not only in terms of cause and prevention but also in terms of education and rehabilitation efforts.” Wide variations in recognition of disabling conditions and in societal response to these conditions characterize the world today. With increased globalization and the concomitant augmentation of intercommunication and interdependence, it has become necessary to examine disability issues in cross-cultural contexts in order to remedy the negative consequences of the current fragmentation of study and publication in the field. Conclusions that can be drawn from the above review of the literature include:

- Disability is a “socially constructed and historically mediated phenomenon.” (Peters, 1993, p. ix)

- Dominant ideologies in different locations are neither natural nor unquestionably right.
Dominant ideologies tend to change with time.

Iledologies emerge from a social context and are culture specific.

Iledologies are grounded and deeply rooted in their social-cultural contexts and may not survive or thrive when transplanted to a different context.

Special education is a complex endeavor.

It is imperative to listen to consumers of special education services [self-advocates and parents of children with disabilities] and to keep in mind the international disability movement’s motto: “Nothing about us without us!” when designing and implementing research studies that focus on issues that pertain to persons with disabilities.

It is essential to advocate for equal opportunities and full participation of persons with disabilities in every aspect of social, economic, political, and cultural life, because as John F. Kennedy said: “All of us do not have equal talent, but all of us should have an equal opportunity to develop our talent.”

It is necessary to speak out against oppression, stigmatization, and stereotyping and to promote democratic policies, because as Martin Luther King Jr. said: “Injustice anywhere is a threat to justice everywhere” (Letter from Birmingham jail, April 16, 1963).

Summary and Transition

After presenting the research problem and its context in the previous chapter and because no publications relating to the issues examined in this study were found, this chapter provided a general review of the professional and research literature about the perspective of parents of children with disabilities and the role they play in educating them. It also pointed out that until recently two key perspectives have received less attention in the literature: (1) the perspective of families (direct accounts by parents, siblings, and other family members, i.e. family voice rather than professional voice) and (2) a more global cross-cultural perspective that does not revolve around western settings.

As is the case in qualitative studies, because it is impossible to predict beforehand what issues and theoretical concepts will emerge during fieldwork, literature that relates to this study’s empirical findings is discussed in the final chapter (Chapter 5) of this report. The next chapter (Chapter 3) describes the research method and the procedures used for conducting the study.
CHAPTER 3
RESEARCH METHOD

A qualitative research approach was used to investigate the phenomenon of educating children with Down syndrome (DS) in Lebanon. Given the nature of the problem and the purpose of the study, this approach was determined to be suitable for exploring this phenomenon for reasons that include the following:

1. The present lack of systematic information or research about the problem of educating children with DS in Lebanon.

2. The need to explore the topic in order to understand the nature and meaning of the experience of educating children with DS in Lebanon to answer the following questions: What is going on? What are the critical factors in seeking services? What needs to be done to obtain these services? How to go about it?—in the absence of a special education infrastructure.

3. The need to obtain a detailed close-up view of the problem from the perspective of mothers, who along with their children with DS are on the receiving end of these services—when available. This entails gathering intricate details about their attitudes, feelings, values, opinions, thought processes, and experience that are difficult to extract or learn about through more conventional methods of research.

4. The need to develop a conceptual framework of the dynamics of the process that explains the mothers’ experience in order to inform further research, policy or practice development efforts. This is imperative because of the dearth of information on the topic.

This chapter addresses the following issues: (a) the strategy of inquiry and theoretical lens; (b) the method of empirical materials collection; (c) the researcher’s role, background, and relationship with participants; (d) the measures taken to safeguard participants’ rights, their anonymity, and the confidentiality of the information they share; (e) the procedures for selecting informants and participants; (f) the procedures for collecting, recording, and managing empirical materials; and (g) the procedures for analyzing empirical materials. Each of these issues comprises several interrelated procedural dilemmas that must be adequately monitored in order to safeguard the credibility (internal validity), transferability (external validity), dependability (reliability), confirmability (objectivity), authenticity (balanced view of all perspectives), and
trustworthiness (scientific merit or methodological rigor) of the research study. These issues and procedural dilemmas are discussed in this chapter.

**Strategy of Inquiry, Paradigm, and Perspective**

Strategies of inquiry “locate paradigms in specific empirical sites and in specific methodological practices” (Denzin & Lincoln, 1998, p. xv). They comprise the assumptions, skills, procedures, and techniques used by researchers when moving from a paradigm to the collection and analysis of empirical materials.

The grounded theory approach to qualitative inquiry, as described by Straus and Corbin (1998a), was used to investigate the phenomenon of educating children with Down syndrome in Lebanon. Given the diversity of Lebanese society’s fabric, the exploratory nature of this study, and time limitations, several grounded theory procedures were used in analyzing empirical materials, including: identifying themes, coding, building analytic categories, and memoing. However, no theoretical sampling was done and theory development and verification were not attempted.

Although according to Denzin and Lincoln (1998, p. xviii), grounded theory is a paradigm-free strategy that could be used in both qualitative and quantitative studies, most of grounded theory research is associated with either the postpositivist or the constructivist paradigms. Glaser and Strauss, the originators of this strategy of inquiry, have both used this methodology within the postpositivist paradigm. However, the work of Glaser and his colleagues remains ingrained in the postpositivist realm, close to the positivist end of the continuum, whereas the work of Strauss and his colleagues has moved closer to the constructivist end of the continuum (Charmaz, 2000). For instance, Charmaz added an interpretive constructivist approach to grounded theory which “places priority on the phenomena of study and sees both data and analysis as created from the shared experiences of researcher and participants and the researcher’s relationships with participants” (2002, p. 677).

In this study, I adopted a middle ground stand between postpositivism and constructivism. I essentially assumed a postpositivistic position reminiscent of Strauss and Corbin’s, but with a stronger inclination towards constructivism. Such a stance accommodates my long-standing concern for the scientific adequacy of research, which has always co-existed with my belief in the social construction of reality. In addition, I espoused a participatory and advocacy perspective.

**Method of Collecting Empirical Materials**

Individual, face-to-face, semi-structured, long, qualitative interviews were used in this study in order to gather the empirical materials needed for exploring the phenomenon of educating
children with Down syndrome in Lebanon. Besides the fact that interviewing is one of the most commonly used and most powerful (Fontana & Frey, 2000) ways in which we try to understand someone else’s perspective, qualitative interviewing fits grounded theory methodology particularly well (Charmaz 2002; Johnson, 2002; Warren, 2002).

Semi-structured qualitative interviewing is a type of “guided conversation” (Kvale, 1996; Rubin & Rubin, 1995) motivated by an interest in and a commitment to understand the experience of people regarding the phenomenon under investigation and the meaning they make of that experience. In this type of interviewing, participants are viewed as “meaning makers,” not “passive conduits for retrieving information from an existing vessel of answers” (Holstein & Gubrium, 1995). The qualitative researcher frames, focuses, and carefully listens to the participants “so as to hear the meaning” of what is being conveyed (Rubin & Rubin 1995, p. 7) in order to uncover themes and patterns from what people say and the way they say it. The themes and patterns thus derived provide insights into the issues investigated and might enable the researcher to make inferences about them that could have implications for future research, practice, or policy development.

In general, researchers use semi-structured qualitative interviews in order to get a detailed picture of participants’ experience with the phenomenon under investigation along with their knowledge, beliefs, opinions, and feelings about it. This method gives the researcher and the participant much more flexibility than the conventional structured interview, questionnaire, or survey. It allows the researcher to pursue interesting avenues that emerge in the interview setting. It also enables the participants to provide a fuller and richer account of their experience. Consequently, semi-structured qualitative interviewing generates valuable essential information about the participants’ lived experience and its meaning. It uncovers a range of varied individual stories or accounts of experiences and reveals participants’ thoughts, beliefs, and feelings about them. Therefore, it promotes the development of a more faithful, credible, and authentic conceptualization of the phenomenon (“what is going on?”) being studied.

**Researcher’s Role**

As the sole researcher, I conceived this study and implemented all the procedures it entails, including the interviewing of participants to collect empirical materials. My role as the researcher-interviewer corresponded to that portrayed in the “traveler metaphor,” rather than the “miner metaphor,” provided by Kvale (1996). These metaphors represent two different conceptions of knowledge formation and different approaches to inquiry. In the miner metaphor, the interviewer digs nuggets of essential facts or meanings that are waiting to be uncovered in the participant’s interior and that remain constant, uncontaminated by the miner. Whereas in the traveler metaphor:

The interviewer-traveler wanders through the landscape and enters into conversations with the people encountered. The traveler explores the many domains of the country, as unknown territory or with maps, roaming freely around the territory. The traveler may
also deliberately seek specific sites or topics by following a method, with the original Greek meaning of “a route that leads to the goal.” The interviewer wanders along with the local inhabitants, asks questions that lead the subjects to tell their own stories of their lived world, and converses with them in the original Latin meaning of conversation as “wandering together with.”

What the traveling reporter hears and sees is described qualitatively and is reconstructed as stories to be told to the people of the interviewer’s own country, and possibly also to those with whom the interviewer wandered. The potentialities of meanings in the original stories are differentiated and unfolded through the traveler’s interpretations, the tales are remolded into new narratives, which are convincing in their aesthetic form and are validated through their impact upon the listeners.

The journey may not only lead to new knowledge; the traveler might change as well. The journey might instigate a process of reflection that leads the interviewer to new ways of self-understanding, as well as uncovering previously taken-for-granted values and customs in the traveler’s home country. The transformative effects of traveling are expressed in the German term Bildungsreise—a scholarly, formative journey. Through conversations, the traveler can also lead others to new understanding and insight as they, through their own story-telling, may come to reflect on previously natural-seeming matters of course in their culture. (Kvale, 1996, p. 4)

The traveler metaphor represents the constructivist, transformative, semi-structured interview approach to inquiry that I used in conducting this study. I should note here that I enjoyed interviewing the study’s participants and learned a lot in the process. I kept a professional distance during the interview sessions, but acquired a few new friends at the conclusion of the study.

**Researcher’s Background**

In qualitative research, the researcher is considered “an instrument of analysis” (Strauss & Corbin, 1998a, p. 53). Thus, the researcher’s background and perspective could bias the study’s findings. Since it is impossible for any researcher to “wipe the slate clean” every time an empirical investigation is launched, Strauss and Corbin (1998a) recommended that researchers should describe their backgrounds and perspectives, acknowledge their biases, and take appropriate measures to prevent their biases from seeping into the empirical materials collection and analysis process:

Although some analysts claim to be able to “bracket” their beliefs and perspectives toward data, we have found that doing so is easier said than done. We know that we never can be completely free of our biases, for so many are unconscious and part of our cultural inheritances. We find it more helpful to acknowledge that these influence our
thinking and then look for ways in which to break through or move beyond them. (1998a, p. 99)

Early on, Glaser (1978) detailed the possible biases a researcher as a human being could introduce into a study, but pointed out that accumulated knowledge and experience could increase the researcher’s “theoretical sensitivity”, thus enhancing the researcher’s ability to conceptualize by “transcending” the empirical materials.

. . . included at each state of generating theory is reliance on the social psychology of the analyst; that is, his skill, fatigue, maturity, cycling of motivation, life cycle interest, insights into and ideation from the data. Generating theory is done by a human being who is at times intimately involved with and other times quite distant from the data—and who is surely plagued by other conditions in his life. . . . Within the analyst as the research continues, is a long term biographical and conceptual build up that makes him quite “wise” about the data—how to detail its main problems and processes and how to explain them theoretically. (Glaser, 1978, p. 2)

The above argument is also made for the positive effect that a review of the literature could have on analyzing empirical materials by sensitizing the researcher to the issues, trends, and limitations of the extant professional and research literature relating to the problem being studied. As Dey (1993, p. 63) puts it, “In short, there is a difference between an open mind and an empty head. To analyze data, we need to use accumulated knowledge, not dispense with it. The issue is not whether to use existing knowledge, but how.”

Having grown up in Lebanon and returned to live there between 1997 and 2004, after residing in the USA for over 20 years, I reacquainted myself with the plight of individuals with disabilities in a war-torn country with limited resources and no special education infrastructure. My casual encounters with parents of very accomplished children with disabilities, through my affiliation with several local disability advocacy Non Governmental Organizations (NGOs), made me aware of creative ways that parents have used to obtain services for their children. These include, for the more affluent social class, (a) making regular trips with their children to European destinations to consult with professionals who assess their children’s needs, design intervention programs for them to follow, monitor their progress, and periodically evaluate their development and (2) individually arranging for their children to be included in typical private school programs and agreeing to pay significantly higher tuition fees to defray the cost of adaptations and accommodations, classroom support, and related services. Since the majority of Lebanese parents cannot afford the above two options, most of them compete to secure placements for their children in the limited number of slots available in the programs offered by NGOs that are subsidized by the Ministry of Social Affairs (MoSA). I was saddened to hear that, in some cases, destitute parents have had to abdicate their parental responsibilities by declaring their children as orphans in order to obtain minimal services for them. I was intrigued by the facts that (a) the services provided by these NGOs are too restricted in range to be responsive to the variety of special needs and not extensive enough to meet the country's demand, (b) there is no coordination of efforts between NGOs, (c) there is minimal information about the intervention programs NGOs offer and neither accountability nor quality assurance, and (c) there is no
information about the number of children they serve and about the number of children who do not receive any services, and thus I wandered “what is going on?”

In order to study this problem, I decided that the best approach would be to examine the current status of special education and related services in Lebanon from the perspective of consumers of these services, mothers of children with DS, by listening to their stories—without imposing a “foreign” structure or passing any judgments—valuing their input, developing a conceptual framework that explains their experience, transmitting their voice, and possibly impacting future research, practice, and policy development in the area.

Because of the dearth of information on the topic and since the exploratory study was to be conducted in a different culture that never had a special education and related services infrastructure, a qualitative approach using empirical materials collected through in-person qualitative individual interviews was indicated. Such an approach provides the necessary detailed view of the phenomenon and enables the researcher to obtain intricate details about participants’ experiences, thought processes, knowledge, values, and feelings that are difficult to extract or learn about through more conventional research methods.

Being steeped in traditional quantitative methodology as a result of extensive training and experience in experimental, quasi-experimental, and single subject research designs in the fields of psychology, applied behavior analysis, and education, and being a novice in the field of qualitative research, when faced with the daunting task of unraveling the complex web of slippery terms coined and defined differently depending on authors’ perspectives as well as the general lack of specificity regarding data collection and analysis procedures in the qualitative research literature, I was immediately drawn to the relative “solidity” of the Strauss and Corbin grounded theory approach. I welcomed the clearly delineated systematic procedures and guidelines designed, not only to assist researchers (and give them some confidence) in the empirical materials collection and analysis phases of the study, but also to promote a way of thinking and reflecting on empirical materials in order to create a conceptual rendering of them. Given my research background, I was also comforted by their striving for scientific adequacy in the research process and product. In addition, I appreciated their constructivist penchant, which coincides with my long-standing belief in multiple realities prompted by my undergraduate training in the psychology of perception. Briefly, I felt better oriented and more temperamentally suited to conduct a qualitative research study using the relatively more well-defined qualitative approach described in the Strauss and Corbin version of grounded theory.

**Researcher’s Relationship with Participants**

My goal was to look at the experience of educating children with Down syndrome in Lebanon through urban mothers’ eyes, who by reconstructing their experience highlight its most important aspects. Therefore, I treated the study’s participants as “experts” who have a story to tell that I am interested in, as well as committed to hear, understand, and document.
Because interpersonal communication factors are likely to come into play, and could influence the process in individual, face-to-face, long interviews, I paid special attention to fostering the development of researcher-participant relationships that satisfy the needs of both parties and do not bias the study’s findings. The dynamic relationship between researcher and participants, which develops as interviewing proceeds, begins on the very first contact (Seidman, 1998) and can change in many ways before the project ends. In order to nurture, sustain, and maintain optimal relationships with participants, I emphasized the importance of their contributions in terms of knowledge, experiences, attitudes, and feelings. I expressed my appreciation for their willingness to participate in the study and my respect for their individual perspectives. I also adopted a courteous professional demeanor and was mindful of their individual needs, values, and preferences. To assist me in “personalizing” my relationship with participants, I entered into the Potential Participants’ Database (described in the Selecting Participants section of this chapter), along with the contact method they prefer; the best times to get in touch with them; the times to avoid calling them; their preferences regarding times, places, and dates for interviews; miscellaneous study-related preferences; information related to scheduling and confirmation of appointments; and other pertinent observations or comments. This database helped me streamline the logistics of researcher-participant interaction sessions and assisted me in remembering details of communications with participants from the beginning of the interviewing relationship. It also helped me avoid possible mishaps in scheduling and keeping appointments as well as prevented other potential communication problems that could have had a negative impact on the relationship.

However, while making every effort to establish optimal relationships with participants, I was careful not to undermine my neutrality to the content they communicated in order to prevent bias from seeping in. According to Patton (2002, p. 366): “Rapport is built on the ability to convey empathy and understanding, without judgment.” Therefore, I followed the suggestions offered by Fontana and Frey (2000, p. 650) who wrote that the interviewer must establish “balanced rapport” by being “casual and friendly on the one hand, but directive and impersonal on the other” and “must perfect a style of ‘interested listening’ that rewards the respondent’s participation, but does not evaluate the responses.”

I should note here that at the conclusion of each interview, I asked participants for their feedback about it. I received no complaints about the questions asked or the interview procedure. All participants had positive comments about our interactions that are exemplified by the following comment made by one of them in an email message she sent me after her interview: “It was nice talking to you. It helped looking back at my own experience and thinking about the whole situation. I wish you all the best for the hard work remaining. Don't hesitate if you need any other information.”

**Ethical Considerations**

First and foremost, a researcher has an obligation to respect the rights, values, needs, and desires of participants who are willing to contribute their time to advance the scientific investigation of
an issue that involves them. This is especially important because in-depth long interviews ask respondents to reconstruct their experience as it relates to the subject of inquiry, which might lead them to reveal private aspects of their lives that, if disclosed outside the research context, could leave them vulnerable. In order to protect participants’ rights and prevent ethical dilemmas from surfacing during empirical materials collection, analysis, and dissemination, an assessment of the anticipated risks versus benefits of the study was done. In addition, procedures for obtaining informed consent, for protecting the anonymity of participants and the confidentiality of the information they share, as well as procedures for debriefing them were specified and are presented below.

**Anticipated Risks Versus Benefits Analysis**

There were no anticipated risks or discomforts to participants associated with the study. The probability and magnitude of risks of harm that might be caused by the investigation were estimated to be not greater than those encountered in daily life. On the other hand, the anticipated benefits to participants included the following:

- The opportunity to participate in a qualitative research study.

- The personal benefit of expressing their opinions, crystallizing and communicating their thoughts, as well as venting their feelings in a supportive non-judgmental environment.

  According to Charmaz

  Research participants may find the experience of being interviewed to be cathartic, and thus the interviews may become significant events for them. Furthermore, participants may gain new views of themselves or their situations. Many participants gain insights into their actions, their situations, and the events that shape them. Simply telling their stories can change the perspectives participants take on the events that constitute those stories and, perhaps, the frames of the stories themselves. These shifts in perspective may range from epiphanies to growing realizations. (2002, p. 691)

- The opportunity to have their perspective explored and their voice valued and heard.

- The opportunity to participate in depicting the current status of programs and services for children with Down syndrome in Lebanon.

- The possibility of impacting policy decisions by contributing to the formulation of the constructed reality of their perspective.

In addition to the above-mentioned anticipated benefits to participants, the study could have important implications for researchers, practitioners, and policy makers because it was the first systematic attempt to explore special education and related services issues in Lebanon. Its anticipated benefits include the following:
The findings of this exploratory study constitute a timid first step towards filling the large gap in the research literature pertaining to disability issues in Lebanon in particular, and in the Arab World and the Middle East in general. These findings could also highlight issues and provide a conceptual framework for further investigations that will advance the comparative special education knowledge base.

Since this study focused on the mothers’ viewpoint, it sheds light on the universally undervalued and often overlooked—until recently—side of the special education and related services equation, that of parents and self-advocates. In addition, valuing and drawing attention to the mothers’ voice constitutes a significant departure from tradition in a culture that historically suppressed mothers' expression and blamed them for the birth of children with disabilities, and thus could have an impact on society.

The findings of this study could provide some insights that might be instrumental in improving policy, practice, service delivery, as well as empowerment programs for parents and self-advocates.

**Human Subjects’ Committee Approval**

The Human Subjects’ Committee (HSC) of the Institutional Review Board (IRB) at Florida State University conditionally approved my application for this research study (HSC No. 2009.2651) on May 22, 2009, pending submission of the Arabic and French translations of the Consent Form. I received the HSC formal Memorandum of Approval with the approved stamped three language versions of the Consent Form (refer to Appendix A for copies both memos and three versions of Consent Form) on September 11, 2009.

Since the Consent Form is a sensitive and crucial document for safeguarding participants’ rights and despite the fact that I am proficient in both Arabic and French, I had specified in the Research Method chapter of my prospectus that I planned to have this document translated into Arabic and French by professional translators in Beirut, Lebanon, for the sake of accuracy and currency of language usage. However, I ran into a serious problem with translation quality that I might not have known about if I was not proficient in all three languages. The highly recommended translator I used provided literal translations that did not use people first language, were not faithful to the original—but more akin to hasty simultaneous interpretations—or authentic to the Arabic and French languages. After I discussed my concerns with the translator (choice of words and nuances; preference for commonly used instead of pedantic words; people first, non-discriminatory, non-demeaning, non-patronizing language) and explained some items that are not self-evident and/or are specific to this research project, the revised versions the translator prepared still left a lot to be desired. In order to validate the translations, I decided to send the amended versions for review by native speakers of Arabic and French who live in Lebanon, are proficient in English, and are well-versed in the field of special education. When I received their much improved versions of the documents, I sent them back to the original translator for approval. I did not foresee such a long process, but it paid off since the resulting documents are true to the content of the English original and authentic to the Arabic and French languages.
Procedure for Obtaining Informed Consent

During my first contact—either over the phone or in person—with the individual potential participants identified (refer to the Procedures for Selecting Informants and Participants section of this chapter), I explained the research study’s purpose and method. I then asked them if they were interested in participating in the study. If their response was positive, I briefly went over their rights, the procedures to protect their anonymity and the confidentiality of the information they share, and proceeded to set up an appointment for the interview, at a time and place suggested by and convenient to them. I also gave them my contact information and encouraged them to contact me if they had questions about the study or if they changed their mind about participating.

Prior to beginning the interview on the scheduled date and time, I gave potential participants the Consent Form in the language they chose and asked them to read it aloud. I clarified key points, answered any questions they had, asked them to sign the Consent Form if they decided to participate, and gave them a copy of it for their records. I emphasized that their participation in the study was completely voluntary, that they were free to decide not to participate or to withdraw at any time, and that no incentives or penalties were going to be used to influence their decision.

Procedures for Protecting Anonymity of Participants and Confidentiality of Information Shared

In order to encourage participants to speak freely and to reduce any fear they might have in voicing their opinions, every measure was taken to preserve their anonymity and the confidentiality of the information they share. These measures were observed in all phases of the study and beyond its completion. They permeate the procedures for selecting participants; scheduling interviews; choosing interview locations; accessing, storing, and disposing of empirical materials records, including digital audio recordings; as well as analyzing, interpreting, and reporting the study’s findings. These measures are detailed in the appropriate sections of this chapter.

Debriefing Procedure

Participants interested in the outcome of the research study were asked to write their names and contact information on index cards and to indicate whether they would like to receive a written summary of the study’s findings, attend a presentation about it, or both. All participants indicated that they wanted a summary of the study’s findings, but only five expressed an interest in attending a presentation about it. I will personally hand-deliver or e-mail the summary to all participants. I will also personally contact all
Participants who expressed interest in attending a presentation about the study’s findings to invite them to the LDSA regularly scheduled parent meeting in which this research study’s findings will be discussed. I reassured all participants that: (a) their anonymity will be protected, (b) no individually identifiable information will be disclosed, and (c) the study’s findings will present a composite picture, rather than an individual picture, of the interviews.

**Procedures for Selecting Informants and Participants**

I solicited the help of two informants and recruited 16 potential participants in order to collect the empirical materials needed to explore the study’s research questions.

**Selecting Informants**

I selected two trusted and knowledgeable insiders to serve as informants throughout the duration of the research study. These two informants have different religious and personal backgrounds and are mothers of young adults with Down syndrome. They are charter members of the Lebanese Down Syndrome Association who, over the years, held various elected leadership positions on its executive board. They share a long history of advocating for the rights of children with disabilities. One of them was instrumental in establishing a new self-advocacy non-governmental organization, which she is currently presiding.

These two informants served as good listeners, as sounding-boards, as peer debriefers, as guides, and as facilitators in implementing the investigation. They assisted me, particularly, in identifying cases, in gaining access to potential participants, in developing a better understanding of the participants’ point of view as well as the phenomenon of mothering a child with Down syndrome, and in checking emerging themes. They also reviewed the empirical findings of this study and gave me feedback about their validity, transferability (applicability), and authenticity (fairness/balanced view).

**Selecting Participants**

The rationale for recruiting 16 urban mothers of children with Down syndrome as participants in the study is discussed in this section, which delineates the procedures for identifying potential participants and for contacting them, then describes their characteristics.

**Identifying potential participants.** Soon after I arrived in Beirut, Lebanon, to conduct the research study, I contacted the Lebanese Down Syndrome Association to schedule a meeting with its president and executive board members (a) to discuss my research study, (b) to specify participant criteria, and (c) to request assistance in identifying potential participants from its
membership database who meet these criteria. LDSA had previously expressed its consent to assist me in implementing the study in a letter addressed to the Chair of the Human Subjects Committee (refer to Appendix A). The LDSA board member responsible for maintaining the database identified mothers who meet the criteria for the study, gave them my contact information, and gave me theirs if they expressed interest in participating in the study. LDSA also sent an email message to all the individuals and organizations on their mailing list and an SMS message to all their members about the study. The message encouraged mothers who meet the criteria to participate in the study and included my contact information. I also followed the following procedures to identify potential participants:

- I collected the names and contact information of mothers who expressed interest in participating in the study, after making presentations about the purpose, goals, and procedures of the research study at two of LDSA general parent meetings.

- I solicited the help of the Family Center for Care and Counseling (NGO that provides integrated health, nutrition, and psycho-social services, at reduced rates for low income families) to recruit potential participants. The center’s social worker identified mothers on their client list who meet the study’s criteria, checked with them, and provided me with their names and contact information, if they expressed interest in participating in the study.

- I received many word of mouth recommendations for potential participants. My two Informants suggested a few information rich cases. Some of the study’s participants suggested other mothers for me to interview. In addition, I received several such word of mouth referrals from colleagues, associations, and a variety of sources. For the sake of privacy, I did not initiate contact with the individuals suggested by word of mouth sources. I gave my contact information to the persons or entities that suggested them, and requested that they ask the mothers in question to contact me, if they were interested in participating in the study.

**Contacting potential participants.** Because interviewing involves a relationship between the interviewer and the interviewee, how the researcher gains access to potential participants and makes contact with them influences the development of that relationship which “begins the moment the potential participant hears of the study” (Seidman, 1998, p. 39).

I met a few of the potential participants for this study, in person, when after my presentations at the LDSA meetings, they approached me to express their interest in participating in the study. A few participants contacted me by telephone, in response to the email and SMS messages or to the word of mouth referrals, to express their interest in participating in the study. In order to preserve confidentiality, to set the appropriate tone for the study, and to build a positive foundation for my relationship with interviewees, I personally contacted the other potential participants (the majority) identified through LDSA and the Family Center for Care and Counseling, because I

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22 - As stated in their letter to the Human Subjects Committee, included in Appendix A, LDSA welcomed the “opportunity to assist in this systematic attempt to examine the problem of educating children with Down syndrome in Lebanon from the mothers’ perspective” and consented to help the researcher in “implementing this much needed research project by providing her with contact information on potential participants who meet the study’s criteria.”
was the logical person to do so in view of the fact that I was invested in the project, I knew all its facets as well as its ramifications, and I was able to respond to any questions they might have about it. My first contact with potential participants, generally by telephone, consisted of a brief introduction of the study, an explanation of how I gained access to their contact information, and the scheduling of a “contact visit” (Seidman, 1998, p. 40) to explain the project.

The individual contact visit served four purposes: (1) explain the nature of the study and what was expected from participants, (2) describe the process of informed consent and the procedures for protecting the anonymity of participants and the confidentiality of the information they share, (3) answer any questions the potential participant might have, and (4) determine whether the potential participant was still interested in being interviewed. If during the contact visit the potential participant decided to participate, I solicited some of the basic demographic and background information about her child and family and started to fill out the Background Information About Child and Family\textsuperscript{23} form included in Appendix B, then I determined the best times, dates, and places to interview her, and tried to scheduled interview sessions. If the potential participant asked for some time to think about the study before deciding to participate, I provided her with my coordinates, encouraged her to contact me, if she needed clarification or more information, and set a time to check with her about her decision.

Although the individual contact visits required additional time and effort, they laid the groundwork for interviewing by providing me with the opportunity to achieve a minimum of three goals: (1) get acquainted and interact with potential participants, (2) emphasize the value of the input they could provide and express my interest in and respect for their possible contribution, and (3) find and become familiar with the setting of possible interview sessions. These individual contact visits also increased my contact time with participants, which enhanced the credibility and transferability of the study’s findings. As a result, I had a minimum of three face-to-face interaction sessions with most participants (only two for two participants who chose to complete the entire interview process in one session), in addition to several telephone conversations, and some email communications.

**Potential Participants’ Database**

As I spoke with potential participants, I noted their key characteristics related to the subject of inquiry and flagged “information-rich cases.” Information gathered on participants, beginning with the first contact, included the demographic and historical information specified in the form in Appendix B that I started soliciting from potential participants during the contact visit, if they agreed to participate, and was completed early in the interviewing process. In order to keep track of all such information, I created a Potential Participants’ Database\textsuperscript{24}. This database was kept on my personal laptop computer, which is for my exclusive use. Its primary purpose was to organize

\textsuperscript{23} Questions were asked in an open-ended manner to gather information listed on this form. The form is organized to facilitate note-taking by the researcher. It was not shown to participants in order to prevent the categories listed on it from contaminating their conceptualization of the type of programs and services their child receives.

\textsuperscript{24} This database also had a secondary purpose and included other information about participants, as described in the Researcher’s Relationship with Participants section of this chapter.
and sort information about potential participants. It was instrumental in helping me keep in mind the character of the growing potential participant pool and how it reflected the range of important variations present in the population, for credibility, transferability, and authenticity rather than representation purposes. It also constituted the basis for writing the Characteristics of Participants section of the study’s final report in order to enable readers to assess the trustworthiness of the study’s findings.

One of the reasons for creating the database was my original plan to follow the grounded theory method of theoretical sampling in which empirical materials collection is “driven by concepts derived from the evolving theory and based on the concept of ‘making comparisons,’ whose purpose is to go to places, people, or events that will maximize opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions” (Strauss & Corbin, 1998a, p. 201) in order to develop a theory of the phenomenon under investigation. However, after conducting the first few interviews, I noticed a lot of similarity in the participants’ accounts of their experience and realized that I was hearing the same story from all participants regardless of their varied backgrounds. This being an exploratory study, due to the difficulties in accessing potential participants and associated problems with scheduling interview sessions that I was experiencing, and due to time limitations, I decided to forego the theoretical sampling and theory development procedures. Instead, I determined that the best course of action, under the circumstances, was to analyze the main themes and to develop a clear analytic story of the perspective of urban Lebanese mothers of children with DS that could be elaborated in future research.

Patton (2002, p. 244) wrote that the number of participants to be selected “depends on what you want to know, the purpose of the inquiry, what’s at stake, what will be useful, what will have credibility, and what can be done with available time and resources.” Seidman (1998) also acknowledged that how many participants are enough for a given study depends on every step of the research process and is different for each study and for each researcher, but he offered two criteria for determining when the researcher has enough participants. The first criterion is sufficiency: “Are there sufficient numbers to reflect the range of participants and sites that make up the population so that others outside the sample might have a chance to connect to the experiences of those in it?” (pp. 47-48). The second criterion is saturation of information. Several other authors (e.g., Lincoln & Guba, 1986; Strauss & Corbin, 1998a) have discussed the point in a study at which the researcher is no longer learning anything new. Strauss and Corbin (1998a, p. 143) called it “theoretical saturation,” Lincoln and Guba (1986, p. 202) called it “the point of redundancy.”

In an effort to provide a fair and balanced coverage of the phenomenon investigated, because of the diversity of the Lebanese population, and the fact that the study’s trustworthiness and value hinged on how the group of urban mothers of children with Down syndrome interviewed reflected the range of variation in the population kaleidoscope on important dimensions including, religious affiliation, educational attainment, socio-economic status, and family structure, a larger sample size than projected was indicated. In addition, in order to capture issues relating to finding educational and related services for children with DS during a critical stage in their development, I only solicited the participation of mothers whose children were in the
elementary school age range. For these reasons and because of time and resource limitations, 16 potential participants identified through the procedures described above were selected.

It is noteworthy that this procedure for identifying and selecting potential participants was designed to ensure participant anonymity and to preserve confidentiality. I obtained recommendations about possible participants from a variety of sources (LDSA, Family, informants, or word of mouth), but was the only person to know the identity of those who actually participated in the study. I closely guarded the list of potential participants as well as all empirical materials associated with actual participants during the study’s implementation. They were kept in a locked cabinet in my home, when not in use.

**Potential Participant Attrition**

Four of the potential participants identified through the procedures described above, who agreed to be interviewed, ended up not participating in the study. One of these potential participants decided not to participate when she found out that the interview consisted of open-ended questions. She told me that she did not mind responding to a multiple choice questionnaire, but that it would be too painful for her to discuss—and thus re-live—the experience. Three other potential participants were not able to spare the time for the interview sessions due to personal circumstances and emergencies that augmented their usual work and family obligations, during the 14-week empirical materials collection phase of the study (Oct 1, 2009 to January 14, 2010).

**Participant Characteristics**

The twelve participants in this study were mothers of children with DS who reside in greater Beirut, Lebanon. Table 1 provides detailed demographic information about these twelve mothers. Their ages ranged from the mid-twenties to the late forties. Their level of educational attainment ranged from middle school diplomas to graduate level degrees. Three participants owned a business, two were employed full-time, two worked part-time in family-owned businesses, and the remaining five were homemakers. When asked to rate their income on a scale from one (lowest in Lebanon) to ten (highest in Lebanon), their ratings ranged from 2 to 8 and averaged 5.84, with seven ratings equal to or less than six and five above six.

They were all practicing believers of a variety of religious denominations: eight were Muslim (five Sunni, three Shia), three were Christian (Maronite, Greek Orthodox, and Greek Catholic), and one was Druze. Three participants were married to men from a different religious denomination (one couple was Sunni and Christian, two couples were Sunni and Shia). Ten of the participants were married to the father of their child with DS; one was divorced and recently re-married; one was in the final stages of divorce proceedings. One participant reported a dysfunctional nominal marriage, mainly due to her husbands’ views about their child with DS. The child with DS was the first child of five participants and the last child of the other seven. Two of the participants delivered their first-born child with DS at a young age, 18 and 21.
Table 1: Participants’ Demographic Information

<table>
<thead>
<tr>
<th>Participants</th>
<th>Age (a) Range</th>
<th>Education (b)</th>
<th>Work</th>
<th>Marital Status</th>
<th>Husband’s Education (b)</th>
<th>Husband’s Work</th>
<th>Income Rating (c)</th>
<th>Family Structure</th>
<th>Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>P 1</td>
<td>30-39</td>
<td>Middle School</td>
<td>Beautician Owns Salon</td>
<td>Married</td>
<td>Electrical Engineer</td>
<td>Government Employee</td>
<td>6</td>
<td>Nuclear + Maid</td>
<td>Shia</td>
</tr>
<tr>
<td>P 2</td>
<td>20-29</td>
<td>BT (Accounting)</td>
<td>Homemaker</td>
<td>Married</td>
<td>BT (Business)</td>
<td>Generator Sales/Repair</td>
<td>6</td>
<td>Nuclear + Maid</td>
<td>Sunni</td>
</tr>
<tr>
<td>P 3</td>
<td>40-49</td>
<td>Some college (Law)</td>
<td>Homemaker</td>
<td>Married</td>
<td>Practical Nurse</td>
<td>Salesman</td>
<td>2</td>
<td>Nuclear</td>
<td>Shia</td>
</tr>
<tr>
<td>P 4</td>
<td>30-39</td>
<td>Some college (Decoration)</td>
<td>Part-Time w/ Husband</td>
<td>Married</td>
<td>Fashion Design</td>
<td>Owns Haute Couture Firm</td>
<td>6</td>
<td>Nuclear + Maid</td>
<td>Greek Orthodox</td>
</tr>
<tr>
<td>P 5</td>
<td>40-49</td>
<td>Middle School</td>
<td>Homemaker</td>
<td>Married</td>
<td>Middle School Disabled, Veteran Bus Driver</td>
<td>4</td>
<td>Nuclear</td>
<td>Sunni + Christian</td>
<td></td>
</tr>
<tr>
<td>P 6</td>
<td>40-49</td>
<td>MA (Economics)</td>
<td>Owns Gift Shop</td>
<td>Married</td>
<td>MA (Business)</td>
<td>Real Estate</td>
<td>8</td>
<td>Nuclear + Maids</td>
<td>Maronite</td>
</tr>
<tr>
<td>P 7</td>
<td>30-39</td>
<td>BA (Business)</td>
<td>Owns Clothing Factory</td>
<td>Married</td>
<td>BA (Physics)</td>
<td>Copy writer Advertisement</td>
<td>7</td>
<td>Nuclear + Maid</td>
<td>Sunni</td>
</tr>
<tr>
<td>P 8</td>
<td>40-49</td>
<td>Licensed Optometrist</td>
<td>Part-Time Family Firm</td>
<td>Married</td>
<td>BA (Marketing)</td>
<td>Advertisement</td>
<td>7</td>
<td>Nuclear + Maid</td>
<td>Greek Catholic</td>
</tr>
<tr>
<td>P 9</td>
<td>30-39</td>
<td>BT (Business)</td>
<td>Full-Time Insurance</td>
<td>Married</td>
<td>BT (Electricity)</td>
<td>Owns Computer Shop</td>
<td>4</td>
<td>Extended + Maid</td>
<td>Shia + Sunni</td>
</tr>
<tr>
<td>P 10</td>
<td>40-49</td>
<td>BA (Business)</td>
<td>Homemaker</td>
<td>Married</td>
<td>2-yr. Technical (Accounting)</td>
<td>Section Director Bank</td>
<td>5</td>
<td>Nuclear</td>
<td>Sunni</td>
</tr>
<tr>
<td>P 11</td>
<td>30-39</td>
<td>BT (Preschool Aide)</td>
<td>Full-Time Furniture Sales</td>
<td>Divorced</td>
<td>BA (Business)</td>
<td>Owns Mall</td>
<td>7</td>
<td>Nuclear + Maid</td>
<td>Druze</td>
</tr>
<tr>
<td>P 12</td>
<td>20-29</td>
<td>BA (Psychology)</td>
<td>Homemaker</td>
<td>Re-married</td>
<td>MD</td>
<td>Member of Parliament</td>
<td>8</td>
<td>Nuclear + Maid</td>
<td>Sunni + Shia</td>
</tr>
</tbody>
</table>

(a) Age ranges are provided because participants were not asked about their age. Some of them spontaneously volunteered this information during the interview.
   The researcher estimated the other participants’ ages based on their children’s ages.
(b) BT (Baccalauréat Technique) is a technical high school diploma.
(c) Participants were asked to rate their household income on a scale from one (lowest in Lebanon) to ten (highest in Lebanon).
respectively. One participant delivered her first-born daughter with DS in her mid-thirties, after a string of unsuccessful pregnancies.

The participants had between one and five children (average 2.75 children per family). Table 2 provides detailed demographic information about the participants’ children with DS. These children consisted of four boys and eight girls in the preschool to elementary age range (ages 3 years 9 months to 13 years). Seven children with DS were placed in various degrees of inclusive educational settings and were generally from one to three years older than their classmates. Three children were placed in special school programs, one was in a segregated NGO program, and one was in transition between two NGO programs. Four of the children were bilingual and five were trilingual. Seven of the children had several medical issues, most of which were associated with DS. Two of the children required numerous major medical interventions and extensive periods of hospitalization.

### Procedures for Collecting Empirical Materials

In order to gather the empirical materials needed for exploring the phenomenon of educating children with Down syndrome in Lebanon, I conducted individual, face-to-face, semi-structured, long qualitative interviews with 12 urban mothers of such children. After a note on the languages used during these interviews, this section provides a detailed description of the procedures used to prepare for and conduct them.

### Language Considerations

Although Arabic is the official language of the country, French and English are widely spoken in Lebanon. In fact, the majority of Lebanese people use a mixture of two or three languages when expressing themselves orally. Graduates of Lebanese private schools, that typically implement a foreign (e.g., American, British, or French) curriculum in addition to the one prescribed by the Lebanese government and usually discourage communication in Arabic on their campuses in order to promote fluency in the foreign language they teach, generally tend to be more comfortable speaking and reading either French or English. For that reason, participants in the study were asked, at the outset, about their language preference and the language they chose was

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25 - The common use of foreign languages as primary means of communication in Lebanon is a manifestation of snobishness, a vestige of private school education, a result of the country’s strategic location at the intersection of three continents, a reflection of its multicultural legacy as well as its cosmopolitan character, and a consequence of its tourism-centered economy. It is quite common for people to use words from one or more foreign languages, in addition to Arabic, sometimes in a single sentence, during everyday conversations, as exemplified by the commonly used greeting: “Hi! Keefak? [Arabic for “how are you?”], ça va? [short version of French “comment ça va?”=“how are you?”].
### Table 2: Participants’ Children with DS Demographic Information

<table>
<thead>
<tr>
<th>Participant’s Child with DS</th>
<th>Sex</th>
<th>Age(a)</th>
<th>Medical Issues(b)</th>
<th>Other Issues</th>
<th>Birth order</th>
<th># of Siblings</th>
<th>Languages</th>
<th>Placement</th>
</tr>
</thead>
<tbody>
<tr>
<td>P 1’s child</td>
<td>Male</td>
<td>5 yrs. 4 mos.</td>
<td>Thyroid</td>
<td>--</td>
<td>Last</td>
<td>2</td>
<td>Bilingual</td>
<td>Inclusive</td>
</tr>
<tr>
<td>P 2’s child</td>
<td>Female</td>
<td>8 yrs.</td>
<td>--</td>
<td>Vision</td>
<td>First</td>
<td>3</td>
<td>Trilingual</td>
<td>Inclusive</td>
</tr>
<tr>
<td>P 3’s child</td>
<td>Female</td>
<td>8 yrs. 1mo.</td>
<td>Heart</td>
<td>Vision Overweight</td>
<td>First</td>
<td>1</td>
<td>Nonverbal</td>
<td>Seeking NGO</td>
</tr>
<tr>
<td>P 4’s child</td>
<td>Male</td>
<td>8 yrs</td>
<td>Hernia Urinary Tract</td>
<td>--</td>
<td>First</td>
<td>1</td>
<td>Trilingual</td>
<td>Special School</td>
</tr>
<tr>
<td>P 5’s child</td>
<td>Female</td>
<td>12 yrs. 5mos.</td>
<td>Heart Thyroid</td>
<td>Hearing Overweight</td>
<td>Last</td>
<td>4</td>
<td>Arabic</td>
<td>NGO</td>
</tr>
<tr>
<td>P 6’s child</td>
<td>Female</td>
<td>9 yrs.</td>
<td>Epilepsy</td>
<td>--</td>
<td>Last</td>
<td>3</td>
<td>Trilingual</td>
<td>Special School</td>
</tr>
<tr>
<td>P 7’s child</td>
<td>Male</td>
<td>6 yrs. 8 mos.</td>
<td>--</td>
<td>Vision</td>
<td>Last</td>
<td>1</td>
<td>Bilingual</td>
<td>Inclusive</td>
</tr>
<tr>
<td>P 8’s child</td>
<td>Female</td>
<td>13 yrs.</td>
<td>Heart GI Tract</td>
<td>Urinary Tract</td>
<td>Vision</td>
<td>Last</td>
<td>Trilingual</td>
<td>Inclusive</td>
</tr>
<tr>
<td>P 9’s child</td>
<td>Female</td>
<td>3 yrs. 9 mos.</td>
<td>Heart Thyroid</td>
<td>--</td>
<td>Last</td>
<td>2</td>
<td>Arabic</td>
<td>Special School</td>
</tr>
<tr>
<td>P 10’s child</td>
<td>Female</td>
<td>11 yrs. 10 mos.</td>
<td>Heart</td>
<td>--</td>
<td>Last</td>
<td>1</td>
<td>Bilingual</td>
<td>Inclusive</td>
</tr>
<tr>
<td>P 11’s child</td>
<td>Female</td>
<td>13 yrs. 3 mos.</td>
<td>--</td>
<td>Vision</td>
<td>First</td>
<td>1</td>
<td>Bilingual</td>
<td>Inclusive</td>
</tr>
<tr>
<td>P 12’s child</td>
<td>Male</td>
<td>6 yrs. 4 mos.</td>
<td>--</td>
<td>--</td>
<td>First</td>
<td>0</td>
<td>Trilingual</td>
<td>Inclusive</td>
</tr>
</tbody>
</table>

(a) Ages of participants’ children were computed as of mother’s first interview session.
(b) The children of participants P 5 and P 8 required several major operations and extensive periods of hospitalization.
necessitated the preparation of Arabic and French translations of the Consent Form (refer to Appendix A) that was read and signed by participants. In addition, for my convenience, the background information form and the preset open-ended interview questions were also available in all three languages. Being trilingual and having grown up and lived most of my life in Lebanon, I have both the language skills and the cultural sensitivity to handle any language or cultural issues that might have arisen while implementing this investigation.

When they were given a choice of languages for the Consent Form, most of the participants (eight) chose the Arabic version, two chose English, and two chose French. All interviews ended up being conducted using Arabic as the main language of conversation. However, minimal to substantial portions of most interviews were infused with French and/or English in accordance with participants’ backgrounds and in line with the customary style of verbal communication in Lebanon.

**Location of Interviews**

The interviews took place at locations selected by participants that: (a) were familiar (to elicit comfort) and convenient to them, (b) preserved their anonymity and safeguarded the confidentiality of the information they shared, and (c) were reasonably quiet (to allow for audio recording) and free of interruptions.

The majority (eight) of interviews were conducted in the participants’ homes. The participants, who indicated that they preferred not to be interviewed at their homes, were asked to suggest another appropriate location. Two interviews were conducted in the private office of fashion design workshops that are owned either by the participant or by her husband. Two interviews were conducted at the Lebanese Down Syndrome Association’s office suite, at times when nobody else was present. The LDSA office suite is located in a modern, secure, climate-controlled office building that a Lebanese philanthropist leases to non-profit organizations for symbolic fees. In view of the fact that I frequently have private meetings with individuals working in the field of disabilities in that suite, conducting interviews there did not divulge the research participants’ identity.

There were minor interruptions to most interview sessions due to mobile phone calls, which I encouraged the participants to answer, and due to refreshments (sequence of juice, coffee, and snacks) that participants insisted on offering—true to Lebanese hospitality etiquette—in their homes or offices. These hospitality breaks came in handy during the double sessions requested by two participants. In addition, two participants asked their husbands to drop by to meet me and five participants arranged for their children with DS and their siblings to join us for a few minutes once during the interviewing process.
Length of Interview Sessions

The interviewing process was estimated to last about three to four hours and to require more than one session. Each interview session was scheduled for 90 minutes. This time frame was used because it was estimated to be long enough to meet the goals of the investigation without unduly fatiguing participants.

Setting a time-frame for interview sessions has definite advantages that include the following: (a) it clarifies time expectations and enables participants to free themselves from other commitments for the required period of time, (b) it reduces participant anxiety by promoting consistency and predictability, (c) it gives a chronological unity to the interview session and makes it amenable to subdivision into phases, (d) it allows the researchers to arrange their daily schedule to allow enough time for wrapping-up, for writing post-interview notes, and for transportation between scheduled interviews, and (e) it facilitates the scheduling task for both the researchers and the participants.

Ten of the 12 participants completed the interviewing process in two sessions each. The other two participants chose to complete the interviewing process in one long session, instead of two. In these cases, I closely monitored their level of fatigue and inserted breaks as needed.

The total interviewing time for each participant ranged from 2 hours 25 minutes to 4 hours 40 minutes, with an average of 3 hours 15 minutes. The total interviewing time for all participants was 39 hours. It should be noted here that the total contact time with participants exceeded by far the 39 hours total time for the actual interviewing process. Unfortunately, total contact time was not documented because of the logistics of keeping track of the duration of the contact visits, the casual face-to-face conversations before and after interview sessions, and the several telephone and email communications with most participants.

Scheduling and Confirmation of Interview Sessions

All interview sessions took place at times selected by the participants. They were scheduled to minimize intrusion on the flow of their daily activities and to prevent unwarranted disruption of their personal environment.

During the contact visit, as soon as potential participants agreed to participate in the study, I asked for their time and location preferences and attempted to schedule interview sessions. If appointments were not set by the end of the contact visit, I asked participants about the best times and the best methods (that will preserve their anonymity as participants in the study) to contact them in order to schedule interview sessions. All participants had personal mobile phones, which made it easy to contact them directly.
Whether I scheduled interviews with potential participants during the contact visit or got back to them at a later date to do so, I contacted them the day before the agreed-upon date and time for the interview to confirm the appointment. In addition, on the day of the interview, shortly prior to setting off to meet them at the designated time and place, I contacted them again to make sure that they were going to be there. This double checking was needed for cultural reasons and because of the level of unpredictability associated with the situation in Lebanon.

Ten participants were very cooperative and, barring sickness in the family or emergencies, did not need to re-schedule any sessions. Two participants cancelled scheduled interview sessions, repeatedly, for a variety of reasons. In fact, one of the latter cancelled so many appointments—because she was in the process of finding a new placement for her daughter—that six weeks elapsed between her first and second interview sessions. Because of the participants’ demanding schedules, the need to re-schedule many interview sessions, and several religious or national holidays, it took 14 weeks to complete the interviewing of 12 participants. It should be noted here that despite my persistent efforts, it was not possible to schedule any sessions with three potential participants who wanted to be interviewed, but were unable to free themselves for the required amount of time during the period in which empirical materials collection took place.

**Spacing of Interview Sessions**

I decided to use more than one 90-minute session to conduct each participant’s interview essentially in order to minimize intrusion into their daily lives and to ward off fatigue, but also because using more than one session guarded against catching them on off-days and allowed me to establish a stronger relationship with them. In addition, the time and effort required to complete the interviewing process, might have demonstrated to participants my interest in, as well as my commitment to hear, understand, and document their story, thus underscoring my respect for and the importance of their perspective.

Interview sessions for each participant were scheduled from three days to a week apart. This allowed enough time for the participants and for me to think about the preceding interview session without breaking the continuity between the two. Most participants completed both interview sessions within that time frame. However, as mentioned earlier, there was a six-week interval between interview sessions for one of the participants.

**Interview Procedure**

Individual, face-to-face, long qualitative interviews were used in this study to ask participants to reconstruct their experience and to explore the meaning they ascribe to it. Tapping into participants’ experience to discover what they think, believe, or feel about it is a difficult endeavor and there is no prescribed formula for successfully completing the process. What

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26 - If the contact visit was conducted in person, I had a minimum of three individual face-to-face meetings with each participant.
amplifies the difficulty of the interviewing process is the fact that it is context-bound. Context factors such as the structure of the interview session, the type of questions, the techniques, the interviewer-participant relationship, and the interviewer’s personality influence the interview’s outcome.

The complexities of developing and maintaining an optimal researcher-participant relationship were discussed earlier in this chapter. It goes without saying that the interviewer’s personality pervades that relationship, determines the style of interaction, and probably influences the outcome of the interview. While some would argue that interviewing is an art, a reflection of the interviewer’s personality, and therefore cannot be taught, Seidman, (1998, p. 78) believes that “the most important personal characteristic interviewers must have is a genuine interest in other people” along with a profound awareness that other people’s stories have intrinsic value and could enhance the interviewer’s own experience. According to him, this attitude constitutes the necessary foundation for learning interviewing techniques and practicing its skills.

In this study, I used semi-structured interviews to explore participants’ experience and the meanings they ascribe to it. The interviews followed a guided conversation format in which I asked open-ended questions and let the participants do most of the talking as they gave an account of their experience. I actively listened, followed up on what participants said to get clarifications, elaborations, or concrete details, and I exercised enough control over the interview process to keep it on track and moving.

At the beginning of the first interview session, each participant was asked to read aloud the Consent Form in the language of their choice. After completing the procedure for obtaining informed consent, participants were asked to describe their child with DS and some of the demographic and historical information included in the form entitled Background Information about Child and Family 27 in Appendix B, was gathered. This opening phase of the interviewing process was designed to help participants to overcome any initial tension they might have, to make them feel more comfortable interacting with me, and to give them the opportunity to practice and gain confidence in their role as “research participants” by answering simple questions. In addition, this initial phase was designed to help participants get accustomed to the audio recording procedure. It definitely helped relieve the anxiety of one participant, who was reluctant to get involved in the study when she found out about the necessity of digitally audio recording the interviews, but changed her mind, signed the consent form, and proceeded to recount the intimate details of her experience.

The Interview Questions included in Appendix C, guided but did not dictate the course of the interview. These questions represented a map of aspects of the phenomenon that I was interested in exploring. During the interviewing process, this map helped me to occasionally monitor coverage of important issues and to determine which issues needed to be explored further. However, since I viewed the participants as experts and wished to enter their world view, as far as possible, and because the participants could uncover aspects of the phenomenon under

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27 - Questions were asked in an open-ended manner to gather information listed on the Background Information About Child and Family form. This form was designed to facilitate note-taking by the researcher. It was not shown to participants in order to prevent the categories listed on it from contaminating their conceptualization of the type of programs and services their child receives.
investigation that I had not thought of, I followed the participants’ lead and explored the areas that arose. This flexibility definitely enriched the empirical materials gathering process and improved its authenticity.

**Interview Questions**

I used open-ended questions in conducting the interviews for the study. According to Seidman (1998, p.69) “an open-ended question, unlike a leading question, establishes the territory to be explored while allowing the participant to take any direction he or she wants. It does not presume an answer.” Open-ended questions give participants the opportunity to reconstruct their experience according to their own notion of what was important, without guidance from the interviewer. At least two types of open-ended interview questions have been described in the literature: (a) “grand tour” questions in which the interviewer asks the participant to reconstruct a significant segment of an experience (a variation, “mini-tour” questions, ask for reconstruction of a time limited span of a particular experience), and (b) open-ended questions focusing on the subjective aspect of the participants’ experience (e.g., “What was that like for you?”).

In qualitative research, interview questions cannot be predetermined before the study begins. They evolve as the researcher is sensitized to the meanings that the participants bring and become more focused as themes emerge. The set of questions presented in Appendix C, cluster around four issues related to the phenomenon explored in this study. As I previously pointed out, in the Interview Procedure section of this chapter, these questions served as a map of the territory being explored. They were useful in facilitating interviewing when I employed them (a) as a point of departure for collecting empirical materials or (b) as a guide for interviewing participants who were not very articulate or those who required prompting to reconstruct their experience. However, these questions were not used verbatim or in the order they appear on the form. In addition, they were refined, supplemented, or discarded as needed during the interviewing process.

In my effort to adequately cover issues related to the phenomenon explored in this study, I used the six types of questions described by Patton (2002, pp. 348-351): (a) background/demographic questions asked in an open-ended manner to elicit the participant’s own “categorical worldview”, (b) questions that call for description of “behaviors, experiences, actions, and activities that would have been observable had the observer been present” (e.g., if I would have been with you during your meeting with the principal, what would I have seen you do, hear you say, etc.), (c) “sensory questions [that] ask about what is seen, heard, touched, tasted, and smelled” (e.g., if I walk through the door of the NGO program your child is enrolled in, what would I see, hear, smell, touch?), (d) questions about opinions, judgments, and values to understand participants’ cognitive and interpretive processes (e.g., “what do you think about . . . ?, what would you like the outcome to be?”), (e) feeling questions that tap participants’ emotional responses (e.g., how do you feel about . . . ?), and (f) “knowledge questions that inquire about the respondent’s factual information—what the respondent knows” (e.g., what are your child’s rights?).

In order to build the confidence of participants in the value of their contribution and to steer clear from hard-to-pin-down general responses, I made it a policy to ask clear singular “what”
questions calling for concrete details of participants’ experience before exploring their opinions, judgments, values, and feelings about it. In addition, I refrained from using “why” questions because they presume “cause-effect relationships, an ordered world, and rationality” (Patton, 2002, p. 363) and because they could make participants defensive since they insinuate doubt about the rationale for the experience in question.

Finally, when formulating interview questions, I kept in mind the fact that they consist of more than just a format and a sequence of words that convey a certain query. Their nature is modified by at least two aspects of the interview setting. Since they are delivered orally in a face-to-face interview, they might have different connotations when associated with variations in speech pattern, voice attributes, facial expression or body language. In addition, since they are posed in a verbal interaction context, their point of insertion into the conversation could also alter their intended purpose. This context-dependency of interview questions discounts the usefulness of preset questions and lends credence to the conversational approach to interviewing promoted by Kvale (1996) and Seidman (1998) among others. Proponents of this approach are likely to agree that

The truly effective question flows from the interviewer’s concentrated listening, engaged interest, in what is being said, and purpose in moving forward. Sometimes an important question will start out as an ill-defined instinct or hunch, which takes time to develop and seems risky to ask. Sometimes the effective question reflects the interviewer’s own groping for coherence about what is being said and is asked in a hesitant, unsure manner. (Seidman, 1998, p. 77-78)

**Interview Techniques**

While conducting the interviews for this study, I used the following techniques that I gleaned from the interviewing literature:

1. *If the participant is anxious, clarify the purpose of the interview, start with the least threatening questions, take it easy, and remain calm* (Keats, 2000, p. 138). Possible causes of anxiety include the participant’s feelings about the subject of inquiry (e.g., fear, guilt, shame, and confusion), low self-esteem, and audio recording.

2. **“Listen more, talk less”** (Seidman, 1998, p. 63). The most important skill in qualitative interviewing is listening. According to Seidman, interviewers must listen on at least three levels: (a) “They must concentrate on the substance [of what the participant is saying] to make sure that they understand it and to assess whether what they are hearing is as detailed and complete as they would like it to be.” (p. 63), (b) they must listen for the participant’s “inner voice” not the outer, more public voice which is inevitably guarded and audience-conscious, and (c) they must listen while remaining conscious of the process (duration, coverage of issues, progression) as well as the substance of the interview. “They must be sensitive [particularly] to the participant’s energy level and any nonverbal cues he or she may be offering” (p. 64).
3. “Follow up on what the participant says” (Seidman, 1998, p. 66). I listened actively and built on the information the participant shared by asking follow-up questions to get clarification or concrete details, or by requesting stories.

4. “Ask questions when you do not understand” (Seidman, 1998, p. 66). When the context or the specific referents of a participant’s account of her experience were not clear, I asked for clarification. This is important for reasons that include the following: (a) asking for clarification indicates that the interviewer is listening and interested in hearing more, (b) participant responses are linked and cumulative therefore not having understood something early in the interview could undermine the whole process, (c) the chronology (time context) of a participant’s experience is often difficult to trace, but essential for understanding it, (d) the participant’s use of vague words without defining what she means by them and without linking them to explicit referents could lead to erroneous conclusions that would jeopardize the credibility and transferability of the study’s findings. Needless to say, questions seeking clarification must be phrased carefully in order to avoid making participants defensive.

5. “Ask to hear more about a subject” (Seidman, 1998, p. 67). I asked questions when I thought I was getting general responses lacking details, when I felt that I had not heard the whole story, or when I was interested to hear more about a subject.

6. “Ask for concrete details” (Seidman, 1998, p 72). In order to keep the participants input grounded and to avoid ending up with hard-to-pin-down generalities, I always asked for concrete details of participants’ experience before exploring their opinions and attitudes about it.

7. “Explore, don’t probe” (Seidman, 1998, p. 68). Seidman wrote that he associates the word “probing,” which is often used in the literature to refer to the skill of following up on what participants say, with the image of a “sharp instrument pressing on soft flesh” and with “a sense of the powerful interviewer treating the participant as an object” (p. 68). He recommended using an alternative term “exploring” and he cautioned against “shift[ing] the meaning making from the participant to the interviewer” through “too much and ill-timed exploration of the participant’s words [that] can make him or her defensive” (p. 68).

8. “Ask real questions” (Seidman, 1998, p. 69). Seidman defines a real question as “one to which the interviewer does not already know or anticipate the response” (p.69).

9. “Avoid leading questions” (Seidman, 1998, p. 69). According to Seidman “[a] leading question is one that influences the direction the response will take” (p.69). The lead could be either in the intonation, syntax, wording, or conclusion implied in the question, or in the interviewer’s own nonverbal or body language (Kvale, 1996; Seidman, 1998).

10. “Follow-up, don’t interrupt” (Seidman, 1998, p. 70). In order not to interrupt participants’ train of thought, I noted key words or phrases they used in describing their experience and waited for a pause in their response to ask follow-up questions about those words and phrases.
11. “Ask participants to talk to you as if you were someone else” (Seidman, 1998, p. 71). If I thought I was only hearing the participant’s public voice, I asked her to pretend that she was talking about the subject with someone she is very comfortable discussing the topic with (e.g., friend, husband, or mentor).

12. “Ask participants to tell a story” (Seidman, 1998, p. 71). I sought concrete details by asking participants to tell a story that illustrates their experience or an aspect of it. According to Seidman, this technique works best with people who consider themselves good story tellers. It could bring their experience to life and make it memorable.

13. “Keep participants focused” (Seidman, 1998, p. 72). I exercised enough control over the interview process to keep participants focused on the topic and to move it forward.


15. If a participant appears acquiescent and provides “socially desirable” responses only, ask for clarification and elaboration to obtain more depth (Keats, 2000, p. 140). Although acquiescence could be due to shyness or politeness, it might also be motivated by participants’ desire to please or need for approval manifested by displaying a positive façade to mask their real thoughts and feelings.

16. “Avoid reinforcing your participants’ responses” (Seidman, 1998, p. 74). Reinforcing what participants are saying with short affirmative responses (e.g., “uh huh”, “O.K.”, or “yes”) to show that the researcher is listening could distort how they respond. A more effective and less intrusive method to demonstrate researcher interest in and attentiveness to participants’ responses is to refer to what they said earlier in the interview.

17. “Share experiences on occasion” (Seidman, 1998, p. 73). When used sparingly, the interviewer’s sharing of a personal experience which connects to that of a participant might encourage the participant to use her inner voice. However, overuse of this technique could distract participants and bias the study’s findings.

18. Avoid responding to excessive questions from participants or providing personal opinions on the matters discussed by feigning ignorance [“I really don’t know enough about this to say anything; you’re the expert”] or dismissing the relevance of my opinion [“it doesn’t matter how I feel, it’s your opinion that’s important”] (Fontana & Frey, 2000, p. 660).

19. “Ask participants to reconstruct, not to remember” (Seidman, 1998, p. 73). Instead of asking: Do you remember your experience with . . . ? thus evoking memory limitations, ask “What happened . . .?” or “What was your . . . experience like?” (p. 74). Reconstruction is based partially on memory and partially on what the participant retrospectively thinks is important about past events.

20. “Explore laughter” (Seidman, 1998, p. 74). Because as Studs Terkel said “a laugh can be a cry of pain, and a silence can be a shout” (Parker, 1996, p.165, quoted in Seidman, 1998, p. 75), examining participants’ type of laughter (e.g., self-deprecating, nervous, ironic, response
to something self-evidently funny) and its juxtaposition with their verbal communication could provide valuable insight into the message being conveyed.

21. **Carefully observe and record participants’ use of the four modes of nonverbal communication:** (1) use of interpersonal space to communicate attitudes, (2) use of speech spacing and silence in conversation, (3) use of body movements or postures, and (4) use of variations in volume, pitch, and quality of voice (Fontana & Frey, 2000, pp. 660-661).

22. “**Follow your hunches**” (Seidman, 1998, pp. 75). If I sensed a mismatch between participants’ verbal and nonverbal language or if I had a real doubt about their responses, I trusted my instincts, carefully phrased and asked the difficult question that best expressed them. Following hunches could reveal a completely different picture of the experience described as well as release the participants’ inner voice.

23. “**Tolerate silence**” (Seidman, 1998, p. 77). As in other aspects of interviewing, I maintained the delicate balance between waiting after asking a question to allow participants time to reconstruct their experience and jumping in with another question in order to prevent a “pregnant or permissive pause” from turning into an “embarrassing silence” (Gordon, 1987, pp. 423, 426, quoted in Seidman, 1998, p. 77). Allowing participants enough time to think about and to add to their responses enhances the quality of the information obtained.

**Procedures for Recording Empirical Materials**

Because qualitative interviewing is concerned with reconstructed experience and its meaning, the empirical materials to be recorded should relate to its substance as well as to its process. This implies that the researcher should note and record verbal, nonverbal, interactional, and contextual details of interviews. In addition, because of the emergent nature of qualitative inquiry, the researcher should keep a log to document significant aspects of the research process. Having provided a detailed description of the procedure used for collecting empirical materials earlier in this chapter, this section focuses on the procedures for documenting empirical materials as well as for maintaining a research process audit trail of the study. Since the procedures for noting and managing participants’ background information were provided in other sections of this chapter, they will not be repeated here.

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28 - Refer to Appendix B and to the Interview Procedure section of this chapter.

29 - Refer to the description of the Potential Participants’ Database in the Researcher’s Relationship with Participants and in the Selecting Participants sections of this chapter.
Digital Audio Recordings

All interview sessions were digitally audio-recorded in their entirety (a) to obtain a full record of the verbal interaction and (b) to allow me to concentrate on the interview process and on coverage of important issues. In order to avoid possible problems associated with equipment, two battery-operated portable digital audio recorders (Sony ICD-P620) were used simultaneously to record each session. I installed fresh batteries in each recorder prior to every interview session. In addition, in order to be ready for all eventualities, I always carried spare batteries in my research briefcase.

Besides producing a complete auditory account of the interview and freeing me from laborious note-taking, the advantages of recording the interviews included the following: (a) getting verbatim quotes of what participants said enriched the research process because each word a participant spoke reflected her consciousness, (b) maintaining eye-contact with and paying attention to participants enhanced rapport, (c) observing nonverbal, interactional, and contextual details of interviews promoted more subtle distinctions and interpretations, and (d) studying the recordings helped me improve my interviewing techniques.

However, audio recording does have its disadvantages. Some participants might refuse to participate in the study because they prefer not to be audio recorded. Other participants might become inhibited or continue to use their guarded public voice, instead of their inner voice. In this study, one participant was, at first, reluctant to participate because of the audio recording, but changed her mind in the opening phase of the interview. However, none of the participants appeared inhibited or used their guarded public voice. On the contrary, they talked openly about their experience and candidly discussed its intimate details.

Interview Notes

In addition to audio recording interview sessions in their entirety, I took quick notes in order to facilitate active listening. These quick notes helped me concentrate on what the participant was saying. They also helped me avoid interrupting the participant and allowed me to keep track of what to follow up on when the timing was right.

I tried to take these notes as quickly and as inconspicuously as possible in order to maintain eye contact with participants. I only jotted down “strategic and focused notes” (Patton, 2002, p. 383) such as words and phrases to capture key concepts, follow-up questions (for seeking clarification, details, stories), and observations or reminders. These notes produced insights on paths to take during the empirical materials collection process and also served as an index to the contents of the audio recordings.
Post-Interview Notes

As soon as possible after the completion of each interview session, I clarified and elaborated on the quick notes jotted down during the session. I also wrote my observations regarding the verbal and nonverbal behavior of the participant, the physical and psychological context, as well as other circumstances surrounding the interview. Bogdan and Biklen (1998) emphasized the importance of writing these notes as soon as possible before talking about the interview with anyone, since talking about such observations, before writing them, might change the way I remember or view what happened. In general, when it comes to note-taking, I heeded the advice of Fontana and Frey (2000, p. 656) who recommended: (a) taking notes “regularly and promptly”; (b) “writ[ing] everything down, no matter how unimportant it may seem at the time,” and (c) analyzing the notes frequently.

Research Log and Audit Trail

In an effort to document the research process and maintain an audit trail, I kept a Research Log summarizing my day to day activities as well as my reflections on the research process. I recorded and maintained information that includes the following:

- Notes about the research process.
- Notes about my personal reactions to and impact on participants.
- Duration of interviews and empirical materials collection.
- Codes, notes about coding process and logic.
- Memos about key issues and concepts emerging from empirical materials.
- Visual representations (images or cartoons) of key issues and concepts identified.
- Memos about questions, thoughts, analysis, interpretations, themes and patterns emerging from empirical materials.
- Notes about possible relationships between participants’ backgrounds and experience
- Notes about techniques used to promote the study’s trustworthiness.
Procedures for Managing Empirical Materials Records

Since there is no one right way to organize the research process and the empirical materials it generates, and in order to use time efficiently as well as reduce anxiety, I created a filing system to store hard copies of documents (e.g., completed Consent Forms and interview notes) relating to each participant and I designed a computer mediated system to manage the substantial quantity of materials generated in the study. The components of that system included:

- The Potential Participants’ Database, described earlier in this chapter, was instrumental in keeping essential information about the participants, including their coordinates in one place and ready for use.

- The original digital audio recordings were kept on the two portable recorders. They were also converted to the MP3 format and imported into NVivo 8 for coding and analysis. Back-up copies of the recordings in their original (DVF) and MP3 formats were kept on my laptop computer and on a USB drive.

- The Research Log; interview and post-interview notes; and analysis notes including memos, codes, and relational statements were kept in word processing software (Microsoft Word) documents on my laptop and were later imported into NVivo 8 for analysis.

- A dedicated email account (mothersperspective@gmail.com) was created to use for email messages related to the research study and for correspondence with participants in order to keep a record of all communications in one place.

A locked file cabinet in my home was used for storing clearly labeled materials relating to participants along with all other records described in this section. I safeguarded the confidentiality of these records and protected the anonymity of participants throughout and beyond the duration of the study. All the empirical materials records remained stored in this locked cabinet accessible only to me and they will be destroyed after the study’s completion or by December 10, 2010.

Procedures for Analyzing Empirical Materials

As is readily apparent from the above discussion, individual, face-to-face, qualitative interviews generate an enormous amount of empirical materials that needs to be reduced to what is most interesting and most important as well as related to research process notes, synthesized, made sense of, and interpreted. What appears to be a daunting task that requires “researchers with extraordinary talents,” is made attainable with hard work and Strauss and Corbin’s (1990, 1998a)
detailed systematic approach to qualitative data analysis, which according to Charmaz (1995, p. 27) “make[s] the strategies of gifted qualitative researchers explicit and available to any diligent novice.”

In Strauss and Corbin’s (1990, 1998a, 1998b) approach to qualitative research, the collection of empirical materials and their analysis go hand in hand. Therefore as soon as I started conducting interviews, I immersed myself deeply in the empirical materials I collected. I listened to the recordings of the previous session(s) of each participant in preparation for the next. I played the recordings several times while doing menial tasks. I took notes about main themes and relationships. I was constantly comparing stories, reflecting on them, trying to make connections, reaching insights and writing memos.

Even though I did not use theoretical sampling and had no intention of developing and testing a substantive theory about the phenomenon investigated, at the beginning of the empirical materials collection phase, I was in a discovery mode—open to whatever emerged from the interviews. Then, as I identified themes and patterns, I asked questions about them in subsequent interviews to determine if they applied and were relevant to other participants, thus switching to a verification mode.

When I imported the digital recordings into NVivo 8 for closer analysis, because of the abundance of the empirical materials and my very slow typing, I decided (a) to enter keywords that reflect what was said, (2) to code directly on the audio timeline, and (3) to transcribe pithy quotable statements only. I translated participants’ quotable statements from Arabic and French into English in order to embed them as illustrations of key aspects of the analysis narrative in the empirical findings chapter. A random sample of my translations was validated by the same two persons who assisted me in preparing the Arabic and French versions of the Consent Form.

After importing my Research Log, interview and post-interview notes, and analysis notes including memos, codes, and relational statements into NVivo 8, while using continual reflection, critical and creative thinking, I explored the complete set of empirical materials by conducting various queries until I identified the main issues, integrated concepts, and developed a clear analytic story line of what seems to be going on that represents the participants’ views.

During the analysis phase of the study, I maintained the research process log and audit trail that was started in the empirical materials collection phase of the study. I also safeguarded the confidentiality of the information shared by participants and protected the anonymity of individuals, roles, and places.

30 - Translation of participants’ quoted statements: In general, only the researcher’s translation into English of participants’ original statements in either Arabic or French, were included as illustrations of key aspects of the analysis narrative. However, if the original statement, in either Arabic or French used expressions or concepts which defy translation due to culture-specific referents, it was quoted in the original language, followed by a literal English translation, and a brief explanation of its cultural connotations.
Procedures Used to Ensure the

Trustworthiness of the Study’s Empirical Findings

Several procedures, inherent to or weaved into the methodology of the inquiry, were used to ensure the credibility (internal validity), transferability (external validity), dependability (reliability), confirmability (objectivity), and authenticity (balanced view/fairness) of the study, which in combination determine its trustworthiness (scientific adequacy or methodological rigor), as defined by Sandelowski (1986). In view of the fact that most of these procedures were described in the appropriate procedures sections of this chapter, they are merely listed in Table 3, which shows how each procedure relates to the five criteria of trustworthiness and to the different phases of this research study. Only the validation procedures used in this study are discussed below.

The member check or participant validation procedure is designed for corroborating findings, in other words, ensuring their credibility (internal validity), transferability (external validity/applicability), and authenticity (balanced view/fairness). It is based on the assumption that participants should recognize and identify with the conceptualization of empirical materials from a study, even if it does not reflect the idiosyncrasies of their case. Although there is some doubt in the literature about its usefulness for that purpose, the consensus seems to be that it is simply another way of generating empirical materials and insights. Furthermore, Schwandt (2001, p. 156) points out that it is “the civil thing to do for those who have given their time and access to their lives to give them the courtesy of knowing (or to honor their right to know) what the inquirer has to say about them.”

After completing the study, I emailed Chapter 4 of this report, which constitutes my analysis of the empirical materials and my conceptualization of the study’s findings, along with the Validation of Findings form, included in Appendix D, to the two informants and to four randomly selected participants, to solicit their feedback. Both the participants and the informants were asked to (a) read chapter 4, (b) rate the empirical findings from one to ten on the three dimensions specified in the form, and (c) provide their comments. Their ratings are summarized in Table 4. Their average ratings on the three dimensions ranged from 8.5 to 10 and their combined ratings averaged 9.5 for credibility (internal validity), 8.7 for applicability (external validity), and 8.8 for balanced view (authenticity/fairness).

Their comments about the credibility dimension included: “Every example or story was closely reflective of personal experience,” “I really recognized a lot of my story with [my child] and I even tried to recognize the stories of other mothers I know. That is why I think that the interpretation is really very faithful,” and “The results of this study demonstrate the current situation of Lebanese mothers searching for the best school placement for their children.” Their comments about the applicability dimension included: “I think that . . . [the findings] correspond
### Table 3: Procedures Used to Ensure the Trustworthiness of the Study’s Empirical Findings

<table>
<thead>
<tr>
<th>Procedures</th>
<th>Measures of Trustworthiness</th>
<th>Phase of Research Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher provides sufficient detail and rich, thick descriptions [verisimilitude]</td>
<td>Credibility (Internal Validity), Transferability (External Validity)</td>
<td>Research report</td>
</tr>
<tr>
<td>Researcher monitors, describes, and interprets how she influenced or was influenced by participants [guards against “going native”]</td>
<td></td>
<td>Research process</td>
</tr>
<tr>
<td>Researcher engages in substantial prolonged contact with participants [reach universal through in-depth exploration of individual experience]</td>
<td>Transferability (Reliability)</td>
<td>Research report</td>
</tr>
<tr>
<td>Researcher solicits feedback from participants about conceptualization of findings [member checks: participant validation]</td>
<td>Confirmability (Objectivity)</td>
<td>Data collection and analysis</td>
</tr>
<tr>
<td>Researcher uses peer debriefers [2 informants]</td>
<td>Authenticity (Balanced View)</td>
<td>Research process</td>
</tr>
<tr>
<td>Researcher does not gloss over discrepancies, analyzes negative cases, reflects typical and atypical elements in findings [guards against “holistic fallacy”]</td>
<td></td>
<td>Data collection and analysis</td>
</tr>
<tr>
<td>Researcher tests for rival hypotheses</td>
<td></td>
<td>Data analysis</td>
</tr>
<tr>
<td>Researcher provides adequate information about what was done and the decision trail [maintain research log or audit trail]</td>
<td></td>
<td>Research process</td>
</tr>
<tr>
<td>Researcher specifies rationale for selection of the sample [sufficient number of participants that reflect diversity in population]</td>
<td></td>
<td>Prospectus</td>
</tr>
<tr>
<td>Researcher describes analytic logic</td>
<td></td>
<td>Research Report</td>
</tr>
<tr>
<td>Researcher demonstrates freedom from bias in the research process and product</td>
<td></td>
<td>Research process</td>
</tr>
<tr>
<td>Researcher presents a balanced view of all perspectives [guards against “elite bias”]</td>
<td></td>
<td>Selection of participants</td>
</tr>
<tr>
<td>Researcher examines and describes her background, experience, research perspective, as well as personal reactions to the research process</td>
<td></td>
<td>Prospectus, Research Report</td>
</tr>
</tbody>
</table>

### Table 4: Participant and Informant Validation Summary

#### Participant’s ratings on a 10 point Lickert scale [1=Strongly Disagree to 10=Strongly Agree]

<table>
<thead>
<tr>
<th>Participants (P)</th>
<th>Credibility</th>
<th>Applicability</th>
<th>Balanced View</th>
</tr>
</thead>
<tbody>
<tr>
<td>P 6</td>
<td>8</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>P 7</td>
<td>10</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>P 8</td>
<td>10</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>P 12</td>
<td>9</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Average</td>
<td>9.25</td>
<td>8.5</td>
<td>8.75</td>
</tr>
</tbody>
</table>

#### Informant’s ratings on a 10 point Lickert scale [1=Strongly Disagree to 10=Strongly Agree]

<table>
<thead>
<tr>
<th>Informants (I)</th>
<th>Credibility</th>
<th>Applicability</th>
<th>Balanced View</th>
</tr>
</thead>
<tbody>
<tr>
<td>I 1</td>
<td>10</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>I 2</td>
<td>10</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Average</td>
<td>10</td>
<td>9</td>
<td>9</td>
</tr>
</tbody>
</table>

#### Combined Participant and Informant ratings

<table>
<thead>
<tr>
<th>P &amp; I Ratings</th>
<th>Credibility</th>
<th>Applicability</th>
<th>Balanced View</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>9.5</td>
<td>8.7</td>
<td>8.8</td>
</tr>
</tbody>
</table>

To many experiences we read about or saw in a variety of contexts,” “I could see a little of everything related to my experience,” and “I recognized myself in the majority of this study’s findings.” Finally, their comments about the authenticity dimension (balanced view/fairness) included: “It is clear that [the study] covers experiences from a relatively diverse community, educationally, socially, financially, and culturally,” and

> This study portrays the current situation very well and takes into consideration the most important aspects of the parents’ journey: the acceptance of their child, the process of finding a good school, the lack of support, the fear, the hesitations, religion, and especially the fact that they know that they can only count on themselves.

In addition, my preliminary findings received an unplanned informal validation when I was invited to present them at a regional conference on inclusive education and diversity in early childhood, which was organized by the Arab Resource Collective and the Department of Education at the Lebanese American University, and held in Beirut, November 5-7, 2009. All the mothers of children with disabilities who attended my PowerPoint presentation (3 from Lebanon, 1 each from Jordan, Iraq, and Syria) spoke to me afterwards to tell me that I described their experience with amazing accuracy. They also thought that my selection of images to illustrate concepts was outstanding.
Summary and Transition

This chapter presented a detailed description of the method used for conducting the research study. It specified the strategy of inquiry and delineated its connection to the paradigm and perspective adopted by the researcher. It identified the method used for collecting empirical materials and provided the rationale for its selection. It described the researcher’s role and her relationship with participants. It specified procedures for selecting participants; safeguarding their rights, maintaining their anonymity and the confidentiality of the information they share; as well as procedures for collecting, recording, managing, and analyzing empirical materials. Finally, it discussed the procedures used for ensuring the credibility, transferability, dependability, confirmability, authenticity, and trustworthiness of the research study. The next chapter (Chapter 4) will present the study’s empirical findings.
CHAPTER 4

EMPIRICAL FINDINGS

The purpose of this qualitative study was to explore critical factors that surround urban Lebanese mothers’ quest for educational and related services for their children with Down syndrome (DS). The intent was to document their experience, to identify key issues, and to develop a conceptual ordering of the phenomenon of educating children with DS in Lebanon that provides a holistic understanding of their mothers’ perspective (i.e., their experience and their views about it). Through my analysis of the empirical materials, courageously and candidly shared by the twelve urban mothers I interviewed, I determined that they go through the following four related processes in their quest for appropriate educational and related services for them:

- Adapting to a new reality
- Pursuing educational programs and related services
- Accommodating to uncertainty
- Preserving self

After summarizing the empirical materials related to these four processes, I will present the key factors in educating children with DS in Lebanon that I identified through my analysis.

Adapting to a New Reality

Every participant reacted to the diagnosis of her child in her own way. One participant whose first child, delivered when she was eighteen, had DS was so distraught that she left her newborn daughter in the care of her in-laws, who offered to adopt her, while she lived in seclusion in a small cottage on their property. She was in deep shock and does not remember what happened during the first two months after her daughter was born. She said that she “suffered from insomnia, was not fully conscious of what was going on, and could not handle going back to [her] home, where [she] had prepared the nursery and everything needed to celebrate the birth of
[her] first child.” She recounted that several times during that period her in-laws lost track of her only to find her “barefoot in the fields gathering herbs and nuts.” When she regained her bearings, her devotion to her daughter’s well-being and optimal development was exemplary.

On the other hand, one participant reported an immediate strong connection to her first born son with DS coupled with a fierce nurturing and advocacy stance. She explained that once your child is delivered: “he pulls your heart with him. You don’t see the eyes, you don’t see the nose, you see nothing . . . you see your soul in front of you. It is just beautiful.” She mentioned that she was so shocked when, soon after delivery, her doctor informed her husband and her that their son needs to be tested because he might have DS that she asked him what DS was, although she had recently studied about it in one of her college courses. What might have helped expedite her recovery from her initial shock was, perhaps, the fact that her husband decided, then and there, to give up their son for adoption. So she promptly gave her husband an ultimatum: “if he goes, I go too!” She forged ahead, at the expense of their marital relationship that suffered and later ended in divorce, because her husband never accepted, and was actually ashamed of, their son.

Most participants, however, reported being shaken by the announcement and a period of shock, disbelief, and depression. They spoke about suddenly finding themselves stuck in a new reality that they could not understand, with a lot to process, a lot to adjust to, as well as a daunting responsibility. In addition to the emotional turmoil due to hormonal changes (“baby blues”) after delivery, the usual stress of recovering from childbirth, the strain of adjusting to the new role of motherhood—for some—and to life with a new baby, the anxiety of dealing with the complex medical issues many of their children experienced, and the fear-provoking unknowns associated with the diagnosis, they attributed their initial response to a variety of factors that are discussed below.

Participants were disturbed by the round-about way they learned about the diagnosis. Although some of them suspected something was going on, due to the unusual behavior of their husbands and the secrecy of hospital staff, many did not find out their child’s diagnosis for about ten days, until the chromosomal test results were completed. Hospital staff generally informed the father of the child first. They usually advised him not to tell his wife until the karyotype confirmed the suspected diagnosis. One participant whose newborn daughter was taken away for unspecified tests soon after birth worried about “all possible diseases cancer, diabetes, kidney problems she might have.” She also wondered why her “usually well-groomed husband stopped shaving, was un-approachable, only showed up when physicians made their rounds, and disappeared with them for what seemed like an eternity.” Since she received no answers to her inquiries, she decided to follow her husband and the physicians out of her hospital room. She fainted when she overheard the physicians telling him “you will get used to her, you will place her in an institution and visit her once a month.”

When they were told that their child had DS, they received no explanation of what that diagnosis meant and what it entailed. One participant assumed that her child’s test results were “down” and quickly dismissed possible issues by thinking: “I’m sure they can fix that.” Most participants were not familiar with the term Down syndrome and the fact that it referred to the better known derogatory label “Mongol.” Once they made the connection, frightening preconceptions,
concerns about stigmatization, and memories of the taunting as well as the mistreatment of these individuals flooded their whole being.

Participants were offended, hurt, and angered by comments made by medical doctors and other professionals like: “Do you want to keep the child?” “Don’t expect much,” “Don’t spend much effort or money on your child,” “Your child won’t amount to much, won’t be independent, and won’t marry.” These statements confirmed their worst fears of the negative reactions their child might face and all the trials their child might endure in a competitive and intolerant society, in which people with disabilities are marginalized.

Whereas husbands, extended family members, and friends were often positive and supportive, some of the participants reported that they found it necessary to distance themselves from certain relatives and friends because of their negative attitudes towards their child. Four participants told me that their husbands had a much harder time accepting their child with DS than they did and according to them two of these husbands still do not believe that their child with DS has any potential and are convinced that “any money spent on them is wasted.” One participant affirmed that, “to this day, [she] refuses to discuss her [child] with people who wanted her to give it up and who disagree with her on the course she chose to optimize the development of [her child’s] potential.”

Participants, who already had children, were concerned about how their newborn child with DS was going to be accepted by them and how they were going to be affected by the child’s disability. A recent conversation one participant had had with her two young sons flashed through her mind and haunted her. Her sons told her that they “preferred not to play with the children with special needs included in their school, because they were different and did not know how to interact with them.” Some participants were apprehensive about the effect of the stigma associated with DS on the future of their other children. One participant asked me whether DS was hereditary, because she was afraid that having a sibling with that condition “might discourage potential spouses from marrying her other children, especially the girls.”

Basically, all participants were frightened and overwhelmed by what they perceived to be an enormous threefold challenge and huge responsibility: (1) meet their child’s needs, (2) fulfill their child’s potential, and (3) fit their child in society. They started worrying about their child’s future from the first day they found out their child had DS, and the question of who will look after their child, when they are gone, will remain their overarching concern throughout their life.

Obviously participants had a lot to deal with at the beginning, but gradually as discussed under the three other processes in the following sections, they came to terms with the “Down syndrome” aspect of their child, and as they moved from preconceived ideas to facts, they internalized their child’s problem and worked fiercely and tirelessly to seek solutions. As one participant explained it, “When your child has a problem, you feel their suffering, their problem becomes your own problem, and you do everything you can to help.”

All participants’ faces lit up and they exuded love when they were asked to describe their child with DS during the interview. They used adjectives like “cute,” “charming,” “handsome,” “beautiful,” “sweet,” “lovable,” “adorable,” “sociable,” “popular,” “pure,” “sensitive,”
“perceptive,” “affectionate,” “caring,” “smart,” and “crafty.” They described their child as an “angel,” “a blessing from above,” “God’s special gift,” “God’s gift of true love and tenderness.” They talked about their “talent for happiness,” their “beautiful smiles that capture your heart,” and their ability to “make you love them.” They praised their ability to “comprehend everything surprisingly well,” to be “reasonable when they understand what and why they need to do something,” and their “super will power” in following medical recommendations. Participants whose children experienced medical problems associated with DS and had to undergo multiple surgeries and treatment regimens, expressed their respect and admiration for the strength their children showed and required from them. These participants reported that they drew strength from their children’s resilience in withstanding the myriad medical interventions they had to undergo.

A few participants credited their children with DS with facilitating aspects of their lives. One participant told me “I feel that [my son] connected me somehow to a world of certain people and places that always turns out positive. That’s what keeps me content and grateful.” She recounted several instances in which they got preferential treatment because of his charm. For example, the owner of the office next door to her office was refusing to let her pierce his walls in order to install an air conditioning system for her office, but he relented when he met her son. Other instances of privileged treatment ranged from the immediate granting of visas that were not issued for them in advance, as required, to the drastic reduction of wait time for seating at his favorite restaurant. She wondered if that was fair, but affirmed that “in so many ways he makes our life easier.”

Another participant said that her daughter with DS was “born under a lucky star,” because even though she had more than her share of serious medical problems and operations, she always pulled through unscathed. She also mentioned that, to her surprise, all the apprehensions she had at every stage of her daughter’s personal development vanished into thin air, because her daughter handled the transitions flawlessly. In addition, she spoke of the surprising ease of finding the perfect placements, services, swimming instructor, ski instructor, drama coach, etc., for her daughter stating that “doors open wherever she goes.”

Finally, two participants described their children with DS as the “glue” that kept their marriages from crumbling. All participants lamented the fact that Lebanese society is not tolerant and generally blind to the qualities of their children with DS, which explains and perpetuates their marginalized status. One participant stated that “social stigma and social ignorance make the experience of raising a child with DS especially tiresome.”

Briefly, it should be emphasized that most participants reported that their first reaction to their child with DS was far from positive. They acknowledged that their views about their child changed drastically over time. Some of them mentioned that they regretted, and were even ashamed of, their initial reaction. They reported that when their child was a newborn all they saw was “Down syndrome,” whereas they currently viewed their child as more like other children than different, perhaps a little slower due to DS, but “with added value,” as one participant put it. They marveled at how a rich experience developed out of a situation that seemed so undesirable at the beginning.
Pursuing Educational Programs and Related Services

The image that came to my mind while listening to the participants’ accounts of their quest to locate appropriate educational and related services for their children with DS was that of the mythical labyrinth. However, the labyrinth in this case had two added levels of difficulty, because embedded in it was an obstacle course and its setting was a politically unstable war-torn country with limited resources.

Before I go on to describe the perils of the participants’ journey through the labyrinth, I should mention that a few participants, who had the financial means to do so, when they became aware of the lack of a special education and related services infrastructure and the limited availability of appropriate programs and trained professionals to meet the needs of their children with DS in Lebanon, opted to look for programs outside the country.

Consider the story of one of these participants who met the medical consultant of a prominent NGO program for children with intellectual disabilities, in a hospital’s waiting room, while her six-month-old daughter was undergoing heart surgery. After introducing himself, he proceeded to urge her to register her daughter in that program, as soon as possible, to guarantee her a place, when she turns two. Infuriated by his poor timing and lack of sensitivity, she told him angrily “if my daughter lives, I will send her to the best schools and universities, and I will never consider enrolling her in that program.” She reported that this incident made her decide to seek help from abroad, because it made her realize that given the prevalence of that doctor’s attitude, it would be impossible for her to find appropriate programs and services for her daughter in Lebanon. Indeed, upon the recommendation of one of her friends, who lived in Europe, she enrolled her eleven months old daughter in an early intervention program delivered at two European locations by a multi-disciplinary team of professionals. That program required traveling with her husband and daughter to one of these locations, for a few days, twice a year. The first day was devoted to assessment. The next day or two, depending on the complexity of the child’s needs, were devoted to teaching the parents how to implement the program designed by the intervention team as well as how to make the necessary materials. The participant in question, whose daughter experienced almost every medical issue associated with DS, continued to follow that program for five years, because of the progress her daughter was making and especially because of the personal support and guidance the team provided her. She stated “I needed help, they surrounded me, they carried me” during very difficult times. A few years later two other participants in this study, upon her recommendation, also enrolled their children in that same program, one for three years and a half and the other for a year and a half. They also appreciated the reassurance, support, and guidance provided by the team. As is readily apparent, enrolling a child in that program was costly, because besides the consultation fees, there were air travel and hotel expenses for the parents and child.
However, when it was time to enroll their children in schools all three of these participants had to
hunt for appropriate educational placements for them and to find their way through the labyrinth.
But, as will be discussed later, they had a distinct advantage over most other mothers of children
with disabilities in Lebanon.

Process of Obtaining Services

In the absence of a special education infrastructure, most of the participants had to fend for
themselves and engage in a time consuming, laborious, and frustrating trial and error process to
secure an educational placement for their children with DS. Four of the six participants, who
found out about the Lebanese Down Syndrome Association (LDSA), sought and benefited from
its guidance and support in this process. Some of the participants who asked Ministry of Social
Affairs (MoSA) [the governmental body in charge of disability issues] for a list of inclusive
schools, were surprised that the only list MoSA had was that of the special programs run by
NGOs. A few participants found the recently published Inclusive Schools Guidebook (Nadjarian,
2008) not helpful, because it was already out-of-date and most schools listed in it only accepted
students with mild learning difficulties in need of remediation. To facilitate her search, one
participant had to resort to a list of schools given to her by the Speech Therapy intern working
with her child. That list was prepared by the university that the therapist was enrolled in, for the
benefit of students seeking practicum or internship sites. Without the benefit of information or
guidance, most participants had to beat the pavement and go from school to school, often facing
rejection, and ending up empty-handed. One participant put it this way: “You look around so
much that you get dizzy, but you get nowhere.” Another participant, when asked to relate her
experience said: “This is going to open old wounds. Actually, they’re still there and not
forgotten.”

As is the custom in Lebanon, relatives, friends, even acquaintances often got involved in the
search process and occasionally provided useful information. However, interpersonal issues
sometimes arose and the information they gathered was usually of questionable value as well as
probably off-target, and it generally caused more confusion, according to some participants.

Obstacles to Obtaining Services

The many obstacles participants faced in their search for appropriate educational placements for
their children with DS included the following:
Availability. According to all the participants in this study, there is a limited number of programs with a restricted number of openings that are geared to serve or equipped to include students with disabilities. As a result, the programs currently available do not match the country’s demand. Thus, participants often faced closed doors, rejection, and sometimes humiliation [e.g., “we don’t admit such children! Your child belongs in a special NGO program’’] in their quest for appropriate educational placements for their children. Some of them were aware that since 2005, the National Inclusion Project (NIP) and later the National Inclusion Program in Lebanon (NIPL) [both described in Chapter 1] have been preparing more private and public schools to include students with disabilities, but wondered what type of children they were targeting. However, given the fact that historically the first inclusive programs in private schools were initiated by mothers, some mothers are still resorting to that measure to secure programs for their children. When unable to find an appropriate placement for her daughter with DS, one of the participants in this study worked with a cooperative school principal, in her neighborhood, to start one for the benefit of her daughter.

Location. Some programs are located outside the greater Beirut area or in distant locations requiring excessive transportation time and expense. Although it was inconvenient, some participants (a) moved their whole household closer to the program, (b) found a second home close to the program, (c) or arranged to stay with relatives who live close to the program until they could move. It should be mentioned here, that one participant whose child was born in another Arab country, where her husband was employed, chose to move back to Beirut, mainly for family support, but also because she thought that programs in Beirut were superior to those in the country in which they were living. In addition, four participants resorted to the three alternatives listed above. Nonetheless, the children of four of the participants in the study ride the school bus for about 45 minutes to an hour, each way.

No quality assurance. According to the majority of participants, since there is no accountability system or monitoring of the programs available and because the only information about them is provided by the programs themselves or their reputation, participants generally struggled when deciding which program would be appropriate for their children. Most participants reported that this was the obstacle that hindered and frustrated them the most. One participant represented their general opinion by stating that she found the “choice-making process very difficult because she did not have enough information and because it was associated with guilt feelings about whether this was what was best for [her child] and whether she was doing enough to promote the maximum development of [her child’s] potential”. It is noteworthy that seven of the participants had to pull their children out of at least one program in which they fought to enroll them, because for a variety of reasons, it did not work out for them.
Language of instruction. Quite often, the language of instruction in the program the participant found most appropriate for her child was not her or her family’s strong foreign language. The language of instruction in most private school inclusive programs is English. The general belief seems to be that it might be easier for a child with DS to become literate in English as a foreign language, than French, because the spelling and grammar are a lot easier to master. Five participants in this study chose a foreign language of instruction that was not their or their child’s strong language and proceeded to learn or strengthen their skills in that language in order to help their child with homework. This is one of the reasons why some of the children of the participants in the study were trilingual.

Cost. According to participants, the programs provided by NGOs are the most affordable and they are subsidized by MoSA. However, most other programs are quite expensive and generally beyond the financial means of the majority of the population. The cost issue will be addressed, in more detail, in the discussion section of Chapter 5.

A few participants pointed out that some of the private school inclusive programs seem to be in the money-making business. Consider the story of one participant who was planning to register her son in one of these schools for the 2009-2010 school year. She decided to enroll him in their summer camp to give him a head-start and to familiarize him with the setting. The camp was scheduled to be held daily, 8:00 AM to 3:00 PM, for two months. As required that participant paid the entire enrollment fees ahead of time. Two days after the camp started, she received a note from the administration stating that the camp hours were going to be shortened (8:00 AM to 1:00 PM) because the children are getting tired. A couple of weeks later, she received another note stating that the second month of the camp was cancelled due to low enrollment. She was completely turned off, when instead of offering to reimburse her for services not rendered, they asked her to pay a supplemental amount—because her child has DS—that they claimed was inadvertently left off her bill. Needless to say, she refused to pay that amount and sought another placement for her child for the school year.

Admission requirements. Even when participants thought they finally found a possible placement they could afford that would meet their children’s needs, they often realized that they had a few more steps to go through. For example, one participant found a possible placement for her six-year-old son in a private school inclusive program that requires a battery of assessments prior to admission. The assessment process took seven weeks to complete. As a result, until a few days before school started, that participant did not know whether her son was going to be admitted or not. He was admitted, but her anxiety level peaked in the process.

Another participant was not as lucky. She lost the opportunity to enroll her three-and-a-half-year-old daughter in another private school inclusive program that had reserved a place for her, pending assessment results. However, the professional who assessed her daughter had gone on maternity leave earlier than expected, prior to completing the assessment report. The participant pleaded with the school to perform their own assessment, to no avail. Having painfully checked all possible placements for her daughter in order to select that inclusive program, the participant had to settle for what she considered a much less desirable alternative, a special school outside Beirut, for the current school year. However, she was
determined to start early and use *wasta*\(^{31}\) to get her daughter admitted in that program for the next school year.

According to a few participants, in at least one private school inclusive program, a child with a disability is only considered for admission, if all the siblings of that child are transferred to that school. The intent of that policy is commendable, because it is based on the principle of including children with disabilities in the neighborhood school where their siblings are enrolled. However, since that principle does not apply to Lebanon and because of the fact that such a policy might lead to several logistical problems for the siblings, most notably main language of instruction mismatch, in addition to disruption of their school and social lives, it constitutes yet another obstacle.

A few participants mentioned that sometimes there appears to be hidden reasons for not admitting a child to a particular program. For example, one participant suspected that she was given the run-around and her son was not accepted in a private religious schools’ inclusive program, simply because his middle name denotes affiliation to a denomination different from that of the school’s, albeit within the umbrella of the same religion.

**Types of Programs**

Seven participants, based on their belief that their children should be educated alongside their typical peers to promote their optimal development, chose to place them in typical private school settings, although some of them realized that most inclusive education programs in Lebanon are still at the experimental stage and that not all of them are currently equipped to provide full inclusion for a variety of reasons, including: the lack of flexibility of the dual curriculum adopted by most schools, the heavy emphasis on academic subjects in the curriculum, the lack of practical (e.g., home economics) and vocational orientation in the secondary cycle, the foreign language of instruction for most subjects, the lack of appropriately trained teachers (e.g., differentiated instruction) and school personnel, and the prevalent negative societal attitude about disabilities. In this context, it should be mentioned that according to several participants in this study, the rate of enrollment of typical students in one of the private schools with an inclusive program is apparently suffering because of the fact that it admits students with disabilities.

A few participants whose financial situation did not allow for an inclusive education option sought employment to defray their children’s educational expenses. In doing so, two of these participants defied their husbands, who discounted the children with DS’ capabilities and potential and believed that any money spent on them was wasted and would be better spent on their siblings. One of these participants told me that her conscience did not allow her to place her preschool-aged daughter with DS in one of the NGO programs subsidized by MoSA because “when you go visit [such] programs, you see sights that could give you a nervous breakdown.”

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31 - *Wasta* is an Arabic word which refers to an intermediary, intercessor, or middle-man, and signifies using someone's influence (clout) or connections to obtain preferential treatment or to get things done.
She added: “children imitate what they see, there’s no telling what aberrant behaviors they’ll learn in these settings.”

Three participants placed their children in special schools. One of these participants took a strong stand against inclusion. According to her, not all children with DS have the academic abilities and potential necessary to enroll in typical schools. She compared including children with DS to “sending high school drop-outs to Harvard.”

A couple of participants settled for enrolling their children in NGO programs, because they had no other choice, since they could not afford to place them anywhere else. These two participants had the lowest level of education in the group, yet when they talked about their children’s behavioral issues, they demonstrated insight and sophistication comparable to that of the best behavior analysts. Although they wondered if their children would have been better off in other programs, they repeated to me several times during their interviews—as if trying to convince themselves or justify their choices—that their children’s future is more secure in these segregated settings, because they were receiving vocational training and they will be employed and supported by the NGOs in their adult life.

Describing Programs and Services

Since most programs do not encourage frequent visits by parents and do not allow parents to visit their children’s classrooms, most participants did not have a clear picture of their children’s educational program. They typically evaluated the programs their children were enrolled in by their children’s attitude, changes in their children’s behavior, samples of work they brought home, their homework assignments, feedback from school (communication book and periodic evaluations), and their meetings with and impressions about staff. Most participants spent a minimum of a couple of hours daily with their children working on homework assignments. The participants who asked for guidance from school personnel and therapists on how to work with their child at home in order to coordinate efforts and reinforce what their children were learning at school, rarely got cooperation.

Some participants had serious concerns about discipline and supervision issues in the programs in which their children were enrolled, as exemplified by the following two stories. One participant, whose gentle affectionate four-year-old son came home so exhausted the first three days of the school year that he went directly to bed and slept for 12 hours, sensed that something was not right. However, when she saw that, contrary to his usual gentle demeanor, he was chasing their cat with a ruler to beat it, she was alarmed. She went to her son’s program the next day to investigate what was going on. Since nobody was in the front office, she went directly to his classroom. Through the window, she observed his teacher repeatedly slapping one of his classmates while all the other children fearfully sat motionless in their seats. So she stormed in, took her son away and pulled him out of that program. Another participant, whose eight-year-old nonverbal daughter came home with torn jeans and undergarments as well as suspicious marks and bruises on her lower body, several times within a month, was unable to get a reasonable explanation from the programs’ administration and staff. So in order to protect her daughter, from what she suspected to be sexual abuse, she withdrew her from that program.
As is readily apparent from the discussion above, finding an appropriate educational program for children with DS in Lebanon is an arduous and frustrating trial and error process that requires perseverance. However, this being Lebanon, the country of paradoxes and surprises, I would be remiss if I do not mention the rare patches of blue in the generally grey sky of educating children with DS that participants in this study pointed out to me. Two participants reported that they were pleasantly surprised by the reaction they got from program administrators when they asked them if they would include a child with DS. One participant, whose four-year-old son with DS was deemed unsuitable for inclusion in all of the prominent day care and preschool programs that she visited, expecting another rejection, decided to call, instead of visit, another preschool in Beirut to ask whether they would admit a child with DS. She could not believe her ears when, after a brief pause, she heard the surprised program director’s reply: "why wouldn't we accept him?" Another participant and her husband, who dropped in to meet me during the interview, were at a loss for words of praise when they described the principal of the private school their 8-year-old daughter attends. They raved about his moral caliber, his philosophy of education, his progressive attitude, and his willingness to initiate an inclusive program at his school for the benefit of their daughter. They went as far as wishing he could be cloned to improve the educational system in Lebanon.

In addition, it is important to highlight the fact that despite the difficulties inherent in the system, the majority of the participant’s children are bilingual, with five being trilingual, and thanks to their educational placements, as well as to their home upbringing, are socially adept individuals with pleasant personalities. One participant who regularly takes her 13-year-old daughter, who had almost all the medical problems associated with DS, for medical consultations and intervention procedures, to a prominent children’s hospital in the USA, made an interesting observation. She reported that all the American professionals, some of whom have children with DS themselves or in their families, who meet her daughter, whom she aptly describes as “épanouie” [French for blossoming], compliment her on her daughter’s high level of functioning. Her daughter is trilingual, has a pleasant personality, a good sense of humor, loves to swim and snow ski, and enjoys the TV serial “Friends” so much that she committed most of the episodes to memory and is currently taking acting lessons with a local theatre group. That participant thanked God that she has the financial resources to take care of her daughter’s needs and to help her become the best she could be. She added that because children with disabilities basically have no rights and since practically nothing is available for them in Lebanon, she took it upon herself to find ways to meet her daughter’s needs and to promote her optimal development. She remarked that “perhaps in the US everyone relies on the government, whereas in Lebanon you have to do it yourself.”
Mothering a child with DS is a journey with lots of ups and downs. One participant described it as an “emotional roller coaster” and another compared it to the board game Chutes and Ladders (also known as Snakes and Ladders). They all agreed that although the journey is sprinkled with joy and delight, it is also laden with fear and uncertainty.

Starting from day one, with the sudden realization of the enormous challenge they faced and the resulting multiplication of their obligations—particularly if their child had medical issues associated with DS—participants reported being so apprehensive, overwhelmed, and preoccupied by their newly acquired huge responsibility that it had an unsettling effect on them and their lifestyles. One participant used the French expression “couper l’herbe sous le pied” [French equivalent to “pull the rug from under the feet”] to describe that state of imbalance, which inevitably perturbs and increases anxiety. Their all encompassing concern for the welfare of their children with DS essentially consumed, even drained, their emotional, mental, and physical energy as well as their time. That time is a precious commodity for mothers of children with DS was amply supported by the facts (a) that 14 weeks were necessary to complete the interviewing of 12 participants and (b) that the time and energy required for juggling their multiple responsibilities prevented three potential participants from getting involved in the study.

The first and foremost concern for all participants was their uncertainty about the future of their children with DS. They appeared to always be thinking about what is going to happen in the future. They worried about what their child will be doing, how their child will survive, where their child will be living, and particularly about who will be looking after their child after they are gone. A few participants had already started trust funds to provide their children with financial security. All participants feared their children will suffer from discrimination and will be vulnerable to exploitation. Participants who had daughters with DS were especially terrified about possible sexual abuse.

In addition to the uncertainties associated with the trial and error process of finding programs and services for their children and the difficulties they faced in paying for them, all participants worried about the quality and appropriateness of these programs and felt unsure whether they were doing enough for their children with DS. They seemed to be constantly wondering: “Am I doing the right thing for my child?” “Am I doing enough?” “What else needs to be done?” “Would my child have been better off if I could afford this other program, this new therapy, those vitamins . . . ,” etc.

Participants whose children had medical issues associated with DS, those who had to move to be closer to programs and services, those who had changes in their marital relationships or in relationships between siblings, had added levels of uncertainty with which to contend. Add to all that, the uncertainties of the situation in Lebanon that impinge on everyone’s life and amplify the effect of all the others, and you get a high dose of anxiety. A few participants credited the 15-
year war for their high tolerance for ambiguity and for their resilience. One participant, after reading the essay “Welcome to Beirut” (http://www.bbbautism.com/beginners_beirut.htm), written by Susan F. Rzucidlo and inspired by Emily Perl Kingsley’s essay “Welcome to Holland” [included in Chapter 1], which compares the experience of having a child with autism to that of being dropped in Beirut in the middle of a war, stated that “Welcome to Beirut really illustrates what we’ve been through. The only problem is that [we] lived both experiences: the bombs and the disability!”

After being shaken by the initial crisis, then recognizing that their life has been changed—forever—all participants gradually resumed their normal life and integrated their child with DS into their usual lifestyle. Although each participant accommodated, in her own way, depending on the idiosyncrasies of her situation, to the uncertainties brought about by the drastic change in her life and the threefold challenge that she faced, they all went through similar processes and used similar strategies. Once they acknowledged the inevitability of the state of uncertainty, they engaged in continuous reflection, self-appraisal, frequent re-appraisal, set priorities, made decisions, came to terms with past and present conditions, and resolved to make the best of the present. They emerged from this self-discovery path determined to fight for their children’s rights. Their perseverance in struggling to provide what their children needed became their means for decreasing uncertainty by reducing the probability of additional issues arising. One participant affirmed “I am determined to keep trying no matter what. When there’s a will, there’s a way. May God give me the strength to continue.”

**Preserving Self**

Participants in this study devoted much effort to maintaining essential aspects of themselves, valued in the past, while forging ahead to fulfill their new demanding role of mothers of children with DS. All participants thought that mothering a child with DS was a growth experience that gave them a deeper appreciation of the importance and value of motherhood. They all affirmed that it made them change their outlook towards life. They developed a “greater understanding of life” “a greater sense of meaning.” The experience “clarified what is important in life” and gave them a “new” or “increased sense of purpose”. It made them “concentrate on priorities” as well as “steer away from and rise above trivialities.” It also highlighted the “importance of planning for the future.” Briefly, it gave them greater maturity.

The enormous threefold challenge and huge responsibility of meeting their children’s needs, fulfilling their children’s potential, and fitting their children in society, launched participants on a discovery path full of opportunities to learn and develop. Essentially, as one of them described it “suddenly, a whole new world, I did not even know existed, was revealed to me, I met new people, learned about all kinds of things, and even learned a new language.” As discussed before, their abrupt immersion into a new reality was daunting at the beginning, but all of them thought it turned out to be an enriching experience. They sought information about DS and about the medical issues their child had, in order to educate themselves about them. This involved searching for information on the internet and ordering books from abroad. They came in contact
with a variety of medical specialist as well as special education and related services professionals. In addition, some of them met other parents of children with disabilities and got involved in the activities of parent associations. As a result, their social and community networks expanded. They learned to function in this new world and mastered the professional lingo. Some of them (five) even got to learn another foreign language, because the main language of instruction of the program in which they chose to enroll their child was not their strong foreign language.

All participants acquired a new set of skills through taking care of their child with DS. As one participant put it: “without [child’s name], I would not have discovered how to be the mother of a child with DS.” Through observation, they learned techniques used by educators and therapists that they applied at home. Some of them even taught their live-in maids to use these techniques. A few of them approached their children’s teachers and therapists, unfortunately with limited success, in order to coordinate efforts and apply at home what their children were learning at school. All of them worked diligently with their children for a minimum of a couple of hours daily. Most of them looked for and participated in training opportunities in the field of disabilities to improve their ability to work with their children. One participant is planning to pursue graduate training in the field of special education.

Most of the participants derived a sense of accomplishment from striving to do their best for their child with DS (a) to fulfill their potential and (b) to ward off possible additional issues from arising. It appeared as if they essentially created a new identity that emphasized “competence in mothering a child with DS” and they were striving to maintain it.

The majority of participants, especially those whose children have medical issues associated with DS, mentioned that their need to juggle their additional responsibilities, to keep track of all their children’s appointments, and to follow up on all the issues concerning them, improved their organizational skills. They reported a “greater ability to focus on what needs to be done as well as to organize and use their time effectively and efficiently.”

The majority of participants reported that the experience of raising a child with DS made them “better person[s].” They reported becoming “more patient,” “less selfish and more compassionate,” “more concerned about others and more interested in helping others,” “more affectionate,” “more open,” “more flexible,” “more adaptable,” and “more tolerant.”

The majority of participants also reported increased personal strength and self-confidence. They talked about becoming “tougher, stronger, more self-assured,” and “more assertive.” They refined their natural advocacy skills and did not miss an opportunity to promote tolerance and awareness of the rights of persons disabilities, in order to pave the way for a more accepting and inclusive society. In addition, they learned how to shield themselves from negative people by bracketing them (support or stay away).

Some participants reported that they enjoyed the lack of routine in their daily life and the frequent problem solving opportunities. They pointed out that besides keeping them on their toes, they “sharpened their problem solving skills, increased their creativity, and allowed them to easily handle issues that others might find difficult to deal with.”
All the participants were practicing believers in a variety of religious denominations. They all acknowledged that the experience of raising a child with DS “strengthened their faith”, “drew them closer to God”, and “enhanced their spiritual growth.”

The majority of participants mentioned that on very bad days they used strategies to pick themselves up as well as to encourage and motivate them to persevere in their struggle: “a huge responsibility associated with perpetual suffering and exhaustion,” as described by one of the participants. About half of the participants reported taking refuge in holy books and prayers as well as learning not to lose hope. Some participants reported seeking the support of their husbands, relatives, friends, and trusted parents of children with disabilities. One participant reported resorting to her scrapbook. She has been collecting stories about the achievements of people with DS, throughout the world, in that scrapbook. She envisions her eight-year-old daughter’s story will be included in it, someday.

Finally, a couple of participants reported that they were taking better care of themselves and paying special attention to their health to be there, as long as possible, for their children with DS.

**Key Factors**

Through my analysis of the empirical materials derived from interviewing 12 urban mothers of children with DS, I identified four crucial elements in educating children with DS in Lebanon: (1) financial resources, (2) mother’s background and characteristics, (3) support, and (4) religion. These vital components of the dynamics of the process of educating children with DS in Lebanon are briefly discussed below.

**Financial Resources**

All the participants, even those from the upper socio-economic classes, complained about the high cost of schooling and therapies for their children with DS. According to the participants and to the *Inclusive Schools Guidebook* (Nadjarian, 2008), tuition fees for children with disabilities in private school programs in Beirut range from about $3,000 to $12,000 per year, as compared to about $2,000 to $5,200 for typical children. When you add to that the cost of pre-admission assessments (up to $700), the expenses of purchasing school uniforms, books, school insurance (about $90 per year), school bus (a minimum of about $100 per month), and additional therapies (about $30 per session, two to four times a week), and miscellaneous other related expenses, the cumulative cost is prohibitive and beyond the financial means of most of the Lebanese population.

It is noteworthy that during the interviewing process, I was struck by the fact that participants who rated their family incomes below five on a scale from one to ten and appeared to have money issues asked me, some of them repeatedly, about how my research study was going to
benefit their children. It seemed to me that they were so desperate to find possible sources of funding to help their children that they tended to explore any potential avenues, however distant.

Mother’s Background and Characteristics

Since my interviews with the twelve participants in this study revealed that mothers appear to be the backbone and the driving force behind seeking appropriate educational and related services for their children with DS, it goes without saying that their personal characteristics pervaded the process. Mothers’ background, personality, and other characteristics played an important role in the four related processes they went through in their pursuit of appropriate educational and related services for their children with DS.

It should be emphasized that all participants in the study were devoted to their children, demonstrated admirable perseverance and resilience, and did not spare any effort to promote their children’s optimal development. However, because of variation in educational backgrounds, socioeconomic status, and other personal traits, some of them had more tools at their disposal to go about it more effectively and efficiently, thus augmenting their natural nurturing and advocacy qualities.

Support

Whatever support participants in this study received was generally serendipitous and unplanned. The three participants who enrolled their children in the European early intervention program were the only ones who profited from the systematic guidance and support of a multi-disciplinary team of professionals, as a fringe benefit of enrolling their children in that program. The support of husbands, extended family members (especially the child’s grandparents), and friends helped the majority of participants weather the storm of having a child with DS and often made a big difference in their adapting to a new reality, pursuing educational and related services, accommodating to uncertainty, and preserving self.

Although ten of the participants’ children were born after LDSA was established in 1997, six of these participants knew about LDSA, but only four of them sought and benefited from its guidance and support. It should be emphasized here that at the beginning most of the participants did not feel they would gain anything by meeting other parents of children with DS for a variety of reasons, including: (a) they felt fragile, were spending all their energy trying to hold themselves together and therefore preferred to orient themselves to their unfamiliar new territory by reading about it, (b) they had a lot to process and were not ready to hear “hollow words” from people who were speaking from a place far removed from their circumstances, or (c) they were convinced that their child was different and they did not want to compare their child to other children with DS. However, with the benefit of hind sight, most of them thought that it would have been helpful to know that they were “not alone” and to learn about positive aspects of the experience of raising a child with DS from other parents in order to re-ignite and maintain their
hope. One participant stated that “tapping into other parents’ experience would have been a great lifeline to get me through some days.”

Religion

Religious beliefs played an important role in the lives of the participants in this study. Quotes from a variety of holy books and prayers punctuated most of the interviews.

Acceptance and duty. The participants’ religious beliefs appeared to help them accept their child’s condition and to strengthen their natural nurturing and advocacy instincts. A substantial number described their child with DS as “a blessing,” “a gift from God.” One participant stated: “what comes from God is welcome and good” and “you cannot return God’s gift.” They seemed to willingly take on their responsibility: “God entrusted me with this child’s care. It is my duty to accept this responsibility and to carry it out to the best of my ability.” One participant who had an especially hard time because her child with DS had to undergo several serious heart surgeries stated: “Difficulties in life are a lot easier than those in the afterlife . . . . I am being tested and my hard work will pay off. My child is going to open the gates of heaven for me.”

Many participants mentioned that when they see other children with severe disabilities or with serious medical conditions, they cannot help but feel that they have no reason to complain, and they thank God that their child only has DS and nothing worse. One of the participants quoted a line from a prayer that expresses this thought: “Thank God for sparing us from what others have been afflicted with and preferred us over many of his creations.”

A few participants criticized mothers who abort fetuses with anomalies or give up less-than-perfect children for adoption. They stated that “some mothers do not have what it takes to raise a child with a disability” and added that they were “pleased and felt blessed that God chose them instead to love and take care of these children.”

No Abortion. One participant, who found out that she was carrying a child with DS, did not consider abortion because of her religious beliefs. Another participant who showed signs of anomaly during her pregnancy chose not to undergo amniocentesis due to the risks involved, but more importantly, because she had no intention of terminating her pregnancy for religious reasons.

Spiritual growth. One participant, who had distanced herself from religious practice, reported feeling a strong need to return to the fold, which she did while pregnant with her child with DS, even though she had an uneventful low-risk pregnancy. Many participants reported an increased commitment to their faith, “enhanced spiritual growth”, and “draw[ing] nearer to God” after the birth of their child with DS. One of these participants is currently pursuing theological training for personal and spiritual growth, not as a career goal.
Summary and Transition

This chapter presented the empirical findings of the research study by conceptualizing four related processes that urban Lebanese mothers of children with DS go through in their search for appropriate educational services for them: (1) adapting to a new reality, (2) pursuing educational programs and related services, (3) accommodating to uncertainty, and (4) preserving self. In addition, it identified four crucial elements in educating children with DS in Lebanon: (1) financial resources, (2) mother’s background and characteristics, (3) support, and (4) religion. The next chapter (Chapter 5) discusses these empirical findings, compares them with the literature, and provides recommendations for research, practice, and policy development.
CHAPTER 5

CONCLUSIONS, DISCUSSION, AND RECOMMENDATIONS

This qualitative study investigated the phenomenon of educating children with Down syndrome (DS) in Lebanon by examining the perspective of urban mothers of children with DS. It was conducted in order to develop an initial understanding of the phenomenon. Although it was exploratory in nature and limited in scope, because it is based on interviews with twelve mothers, some general considerations and conclusions can be drawn from its empirical findings.

This study revealed that, in the absence of a special education infrastructure, mothers are the vital and driving force behind securing educational and related services for their children with DS. It is their unconditional love, their internalizing their child’s problem, their natural nurturing and advocacy skills, their tireless efforts, their perseverance in finding ways to help their children, their resilience in overcoming all the obstacles in their path, and the hours they spend working with them daily, that should be credited for their children’s achievements. It is important to emphasize that, historically, Lebanese mothers have lead the way by initiating the first inclusive programs and, as demonstrated in this study, some of them are continuing to initiate such programs for the benefit of their children.

However, although all the participants in this study did not spare any effort to do the best they could for their children with DS, the type of programs they chose and the level of achievement of their children, unfortunately, appeared to be associated with their financial resources as well as their background and personal characteristics. The high cost of schooling and therapies in Lebanon makes them unaffordable for the majority of the population. The natural nurturing and advocacy qualities of mothers were augmented by their educational background and personality traits.

Whatever support mothers received while adapting to their children’s condition, raising them, and finding appropriate educational and related services to meet their needs, was informal and unplanned. Their religious beliefs appeared to provide meaning and support in these processes.

The portrayal of the current status of special education and related services in Lebanon by the participants in this study reveals an un-equitable, discriminatory, privately run, unmonitored system that lacks accountability and quality assurance, and is in urgent need of comprehensive reform as well as substantial expansion to meet the needs of the country. This revamping of the system should be done at the government level in order to meet the mandate of Lebanese Law.
2000/220, for which no decrees or regulations have been issued to facilitate its implementation ten years after its promulgation.

These considerations and conclusions imply that mothers of children with DS, as well as those of other children with disabilities, are valuable assets that should be supported, empowered, and involved in establishing a more equitable system of providing educational and related services for children with disabilities in Lebanon.

Discussion

Besides discussing the cost of education and related services, I will refrain from commenting about the current status of special education and related services in Lebanon beyond the general conclusion presented above. Due to the limited scope of this study, I believe that my summary of the input provided by its participants should stand on its own and suffice to depict the situation from their perspective. I find it imperative to take this position because of (a) the complexity and the idiosyncrasies of the educational system in Lebanon; (b) the fact that, for comparison purposes, I was only able to find the equivalent of one page of parental opinions about special education services in another Arab country, the United Arab Emirates (UAE), in Crabtree’s (2007, pp. 57-58) qualitative study; and most importantly (c) the inadvisability of using a foreign framework to evaluate it.

However, since in Crabtree’s (2007, p. 58) study in the UAE—which ranks among the fifty richest countries in the world—the Emirati parents complained about the high cost of speech and other rehabilitative therapies, I will briefly address the exorbitant cost of schooling and therapies for children with DS in Lebanon. The cost of these programs and services constitutes a major obstacle as well as a principal source of inequity in securing appropriate educational and related services for children with disabilities in Lebanon. As mentioned in the results chapter, according to this study’s participants and to the Inclusive Schools Guidebook (Nadjarian, 2008), tuition fees for children with disabilities in private school programs in Beirut range from about $3,000 to $12,000 per year, as compared to about $2,000 to $5,200 for typical children. When you add to that the cost of pre-admission assessments (up to $700), the expenses of purchasing school uniforms, books, school insurance (about $90 per year), school bus (a minimum of about $100 per month), and additional therapies (about $30 per session, two to four times a week), and miscellaneous other related expenses such as hiring a shadow teacher (about $400 per month), the cumulative cost is prohibitive and beyond the financial means of most of the Lebanese population. Despite my concerted efforts to locate statistical data on income levels in Lebanon, I was unable to find information about the minimum wage or the range, average, median, mode income. All I could do is highlight the description of the Lebanese economy, provided in Chapter 1, and supplement it with the following information in order to provide a backdrop for evaluating the impact of the high cost of schooling and therapies on the average Lebanese household. As mentioned previously, the Lebanese economy is plagued by unemployment. The Gross Development Product (GDP) per capita Purchasing Power Parity (PPP), a measure used for comparing living standards between countries, was estimated to be US$ 11,500 for 2009 (CIA,
According to a recent country study by the International Poverty Center (Laithy, Abu-Ismail, & Hamdan, 2008, p. 1), “nearly 28 per cent of the Lebanese population can be considered poor and eight per cent extremely poor.” The 2004-05 estimate of per capita consumption (food and non-food consumption, rent, and transportation) was highest in Beirut with a mean US$ 4343 and median US$ 3494 [as compared to mean US$ 2,650 and median US$ 2068 for all Lebanon] (Laithy, Abu-Ismail, & Hamdan, 2008). The distribution of expenditure among the population is unequal. The poorest 20 per cent of the population accounts for only seven per cent while the richest 20 per cent accounts for 43 per cent of the total consumption. The “median per capita consumption [throughout Lebanon] is always lower than the mean because most Lebanese consume less than the average. For example, the consumption expenditure of half of the Lebanese population is approximately 20 per cent of the average consumption level” (Laithy, Abu-Ismail, & Hamdan, 2008, p. 3).

Some of the themes in this exploratory qualitative study’s empirical findings are echoed in the professional and research literature. A brief comparison of this study’s findings with information gleaned from the literature is presented below.

**Announcement of Disability**

The need for physicians (usually obstetricians, neonatologists, or pediatricians) to improve the way in which they deliver post-natal diagnoses of Down syndrome that participants in this study pointed out was documented by Skotko (2005). After analyzing the responses of 985 mothers of children with DS on an 11-page survey comprising yes/no questions, open-ended questions, and ratings of series of statements on a seven point Lickert scale, he concluded that the majority of these mothers were frightened or anxious, because their physicians emphasized the negative aspects of DS and rarely mentioned or emphasized the positive aspects of the condition. These mothers reported that their physicians’ explanations were insensitive, factually inaccurate, and portrayed the condition incorrectly. They were offended by their physicians’ suggestions to offer their child for adoption. In addition the physicians rarely provided up-to-date printed materials or telephone numbers of support groups, or of other parents of children with DS.

**Positive Perceptions and Impact**

Given the prevalence of the medical model in Lebanon, I was pleasantly surprised by the fact that all participants in this study had positive views of their children with DS and described several positive impacts they had on their family. Although Lebanese law 2000/220, set the stage for a qualitative shift regarding disability issues because it promotes a developmental functional model, the medical model still prevails and constitutes a major systemic obstacle to inclusive education for children with disabilities. Under this conceptual model, an internal rather than an external locus for learning difficulties is assumed. For example, failure to learn is attributed to personal characteristics resulting from deficit states (cognitive deficit or disability category) that need to be diagnosed and treated. In contrast, the functional model shifts emphasis toward the external locus of learning difficulties (instructional strategies and environmental factors) and the
social construction of disability (a disabling society rather than individual inabilities and limitations). The prevalence of the medical model in Lebanon is demonstrated by society’s lack of tolerance, stigmatization, and marginalization of people with disabilities, by the present lack of appropriate educational services for them, by the fact that the Ministry of Social Affairs (MoSA) rather than the Ministry of Education (MoE) is the authority responsible for disability issues, and most importantly by MoSA’s exclusive subsidy of segregated NGO programs.

There is increasing recognition in the professional and research literature of the positive perceptions and experiences of families of children with intellectual or developmental disabilities. A few international resources will be briefly highlighted to illustrate this point. Kathryn Soper (2007, p. xxiii) from the USA, edited a book entitled *Gifts: Mothers Reflect on How Children With Down Syndrome Enrich Their Lives*, that includes 63 candid and poignant personal stories submitted by mothers of children with DS that celebrate their experience. Their stories are grouped under five themes: the gift of respect [“respect we gain for our children, for others, and for ourselves”], the gift of strength [“strength they show us, instill in us, and require from us”], the gift of delight [“delight they enable us to feel: laughter, surrender, awareness”], the gift of perspective [“life’s hidden beauties and realities that they make possible”], and the gift of love [“love they call forth from the deepest wellsprings of our hearts”] (Soper, 2007, p. xxiii).

Hastings and Taunt (2002) from the University of Southampton, United Kingdom, reviewed existing research on the topic and proposed a hypothesis that positive perceptions function as individual and/or family resources for adapting to and coping with the experience of raising a child with disabilities. Hastings, Allen, McDermott, and Still (2002), tested that hypothesis by exploring positive perceptions of the mothers of 41 children with intellectual disabilities. They found that mother’s perception of the child as a source of happiness and fulfillment, as a source of strength and family closeness, as a source of personal growth and maturity, were positively associated with coping. In addition, Cunningham (1996) from the Liverpool John Moores University, United Kingdom, who presented an overview of key research findings of the longitudinal study of the Manchester Down Syndrome Cohort which began in 1973, concluded:

> The overall impression of the families and children with Down syndrome is one of normality. The factors that influence their well being and that of the child are largely the same as those influencing any child and family. . . .

> It cannot be assumed that the family or individual members are “at risk” for psychological problems just because one member has Down syndrome. We found that the majority of families (60-70%) in the cohort were harmonious with high levels of family cohesion and perceived satisfaction with life and relatively normal levels of stress. They had adapted positively to their child with Down syndrome and report no persistent negative psychological effects on their lives or their other children. In fact they were more likely to feel the child had positively contributed to the family. (Cunningham, 1996, p. 93)

Kearney and Griffin (2001) from Sydney, Australia, who intensively explored the experiences of six parents of children with significant developmental disabilities, found that although they experienced difficulties, the parents spoke of hope, love, strength, and joy with most of them
seeming to manage with optimism and remarkable resourcefulness. In addition, Stainton and Besser (1998) identified nine core themes: source of joy and happiness; increased sense of purpose and priorities; expanded personal and social networks and community involvement; increased spirituality; source of family unity and closeness; increased tolerance and understanding; personal growth and strength; positive impacts on others/community.

Finally, Heiman (2002) from the Open University of Israel, Tel Aviv, who interviewed 32 parents of children with intellectual, physical, or learning disabilities found that the majority expressed the need for a strong belief in the child and the child’s future, the need to maintain an optimistic outlook, and the need to accept and have a realistic view of the disability.

Uncertainty

The theme of accommodating to uncertainty identified in this study was also documented in the research literature. Mothering a child with special needs was described in one study as mothering “plus extras” (May, 1997). The extras included needing to learn many aspects of caregiving, either through self-education, trial-and-error, or education provided by professionals. This process was described as accompanied by great fear and self-doubt. MacDonald’s (1996) qualitative study of mothers of children with asthma found that the unpredictability of symptoms left mothers confused, scared, and full of self-doubt. The process of mastering uncertainty was described as “forward moving” and associated with an increased sense of control. This sense of control was reached by participants in the present study through perseverance in struggling to provide for their children’s needs as a means for reducing the probability of additional issues from arising, thus decreasing uncertainty. Boydell’s (1996) qualitative study of mothers of adult children with schizophrenia also found that living with uncertainty was the central identifying feature of caring. This was also characterized by the unpredictability of the illness over time, in addition to a cycle of hope, despair, and uncertainty that extended into the future. The theme of uncertainty was also found in other studies described in different words. One mother of a technologically dependent child summarized the theme of uncertainty: “My life is like a 24-hour hell because I’m so scared about what could happen” (McKeever, 1991, p. 213). Briefly, the vulnerability of other-than-typical children and the associated instability and unpredictability made mothers second-guess their efforts, fear that they were not on the right track, not doing enough, or omitting something essential to prepare for their children’s future.

Hope

The importance of maintaining hope in motivating mothers to persevere in fighting for their children’s rights, revealed in the present study’s findings, was also confirmed in the research literature. Larson (1998) suggested a construct, “the embrace of a paradox,” to explain how mothers of children with disabilities cope. He described it as an emotional compromise somewhere between acceptance and denial. Mothers accept their children as they are, but never give up hope for improvement. Larson believed that the embrace of a paradox energizes mothers
and is essential to maternal well-being. He viewed it as allowing for optimism, hope, a positive vision of the future, and personal growth. Support for Larson’s construct is echoed in most of the studies included in Nelson’s (2002) metasynthesis of 12 qualitative studies on mothering children with disabilities. However, there seemed to be a point of diminishing returns. With the increase in intensity and severity of the disability, maternal hope appeared to dwindle although maternal love and commitment did not diminish.

The essence of mothering children with disabilities is eloquently expressed in Nelson’s (2002) conclusion:

It is . . . . necessary to actively work at maintaining sensitivity to the humanity of even the most severely impaired children and to encourage mothers to both acknowledge their children’s strengths and challenge societal definitions of normalcy. Acknowledging and encouraging mothers in their caregiving efforts, acting as a sounding board when needed, and helping mothers gain knowledge and confidence can help to decrease feelings of uncertainty. . . . .

Perhaps the most important practical implication emerging from the data is the significance of maintaining hope in fueling maternal caregiving. Nurses have a unique opportunity to foster hope by working with mothers to plan short-term goals that provide them with a sense of forward momentum. Central to the provision of understanding, meaningful nursing care is remembering the bottom line of maternal caregiving: It is hope that keeps them going and love that sets them apart. (pp. 528-529)

**Positive Adaptations**

Researchers within the last two decades have begun to focus on family strengths that result from having a child with a disability (Singer, Irvin, Irvin, Hawkins, Hegreness, and Jackson, 1993). Research findings suggest that while some families experience low morale due to daily stressors related to having a child with a disability, the majority of families with such children achieve positive adaptation within the family unit (Summers, Behr, & Turnbull, 1989). Positively adapted families have been described as those who “both accept the reality of the disability and are able to love the child for who he or she is; who manage to have successful marriages and emotionally well-adjusted children” (Summers, Behr, & Turnbull, 1989, p. 27). In the present study the families of most of the participants meet the criteria of the above definition of positively adapted families. However, while most families value and accept their child’s disability early on, they are confronted with the challenges and stressors—the nature of which varies over the child’s lifespan—associated with raising a child with a disability.

**Support**

Because adaptation is an ongoing process that begins with the diagnosis of a disability and continues through adulthood, support is needed to help families adapt positively to the variety of
stressors they encounter. The type and quality of support could make a difference in parents’ adaptation by moving them on the continuum from barely surviving to thriving.

Research findings suggest that continual and stable support is provided by the personal social network of a family including family members, friends, neighbors, professionals, and educational systems. Members of this network have been referred to as “help-givers” by Dunst, Trivette, Gordon, and Pletcher (1989) because they can provide the family with material aid (e.g., goods and services), emotional support, information, and referral. In the present study, participants benefited from unplanned informal support of that nature.

In addition to personal social support, personal coping strategies are important for confronting stressors. There is relatively much less research on personal coping resources. Religion as a type of personal coping resource used by parents of children with disabilities has received some attention in recent research studies. In their exploratory qualitative study, which was part of a larger investigation of parent empowerment in families of children with disabilities, Bennett, Deluca, and Allen (1995) found that religion is a strong source of perceived support. Just like in the present study, participants in their study stated that “the child [with a disability] is a gift from God; God chose me because He knew I could handle it; God will take care of things; supernatural healing is possible, and God will give me strength to handle anything that arises” (Bennett, Deluca, & Allen, 1995, p. 306). Similar religious themes were identified in a study by Skinner, Rodriguez, and Bailey (1999, p. 273) who in their qualitative analysis of Latino parent’s religious interpretations of their child’s disability, summarized them as follows: “(a) God sent the child as a means for parents to become better people, (b) God recognized the parents as special individuals capable of raising such a child, (c) the child is a test that God sends to see how parents will respond.” Along these same lines Crabtree (2007) who conducted a qualitative study of care-giving Arab Muslim families of children with developmental disabilities in the United Arab Emirates found that religion ameliorated the social stigma, attached to the child with disabilities as well as the mother, and constituted an example of family resilience. Acceptance of a child’s disability and of God’s mysterious plan was viewed by the mothers she interviewed as integral to their acceptance of Islam. Acceptance of God’s will “brought not merely compensations, but actual blessings upon the home” and the mother of a child with severe disabilities described her daughter as:

... a gift from Allah [God]. He is testing us. Allah gives everyone problems. Sometimes they are financial and sometimes to do with health. He gives us these problems to see how we will overcome them. Since we always look after X [the child] and love her too, Allah will protect us. He gave us a lot when He gave X to us. (Crabtree, 2007, p. 56)

Perhaps the hope and personal strength associated with religious beliefs and practices as well as access to a religious congregation’s social network, are the key ingredients in the strong support that religion provides, as Bennett, Deluca, and Allen (1995) concluded:

Results of this study support previous research findings which suggest that religion is a strong source of support for some parents of children with disabilities. In this study, prayer, church attendance, and several specific religious beliefs were identified as sources of support. The notions of hope and personal strength were identified as effects that
religious beliefs and practices can have on parent’s ability to cope. In addition several parents explained that members and leaders of an organized place of worship can serve as coping resources by accepting the disabled child and supporting the family. Finally, information gathered during one interview suggests that religion may contribute to parent’s sense of empowerment and confidence in his or her ability to create a happy future for the child. (p. 309).

Study’s Contributions and Limitations

Because this exploratory study is the first systematic attempt to examine special education issues in Lebanon, it constitutes a significant contribution to the field for reasons that include the following:

- By being the first scientific study to investigate special education issues in Lebanon, this study initiated the process of filling the information gap on this subject in the professional and research literature, particularly in Lebanon and generally in the Arab World.

- By focusing on participants’ personal experience and the meanings they ascribe to it, this qualitative study provided an “insider,” detailed, close-up view of the phenomenon, in contrast to the “outsider,” distant, panoramic view that would have been provided by a traditional quantitative study.

- By documenting and telling the participants’ story from their viewpoint, without passing judgment, thus giving voice to mothers who have been historically silenced or marginalized, this study initiated the process of valuing their input, empowering them, and involving them in developing a culturally-sensitive and appropriate educational services delivery system anchored on their perspective.

However, since the study’s scope was limited by its exploratory nature, by the fact that it was not funded, and by time constraints, a relatively small number of participants was interviewed. The study’s empirical findings are based on individual, face-to-face, semi-structured, long qualitative interviews with only 12 urban Lebanese mothers of children with DS, i.e., a total of about 40 interview hours. Although qualitative research is done to document the exploration of specific contexts and particular individuals and is generally not concerned with sample representativeness and generalization issues, it should be emphasized that this study’s empirical findings do not represent the perspective of rural mothers and might not reflect all urban mothers’ viewpoints.

Since the study focused solely on urban mothers who live in the greater Beirut area, its empirical findings do not apply to rural mothers or to urban mothers who live outside greater Beirut. As mentioned before, the majority of the Lebanese population is concentrated around urban centers and about half of the population lives in greater Beirut, where most of the programs and services are located. Thus, the special education situation outside greater Beirut and the demographic
characteristics of mothers in that area are bound to differ significantly from those inside greater Beirut.

In addition, although special attention was given to selecting participants from a variety of backgrounds to reflect the complexity and richness of the multifaceted Lebanese society’s fabric, the viewpoints expressed by this study’s participants might not represent all perspectives, values, and beliefs on the subject.

Finally, this initial attempt to investigate the phenomenon, shares the same limitations of other qualitative studies that use interviewing, including dependence on participants’ ability to reconstruct their experience; to introspect in order to sort out thoughts, knowledge, values, and feelings; and the difficulty of observing and interpreting non-verbal and contextual aspects of interviews.

Recommendations

Based on this study’s empirical findings research, practice, and policy issues that need to be addressed include the following:

▪ Train medical doctors and other professionals to be more sensitive to the feelings and needs of parents of children with disabilities. As recommended by Skotko (2005), the postnatal diagnosis of DS should be delivered in a thoughtful and sensitive manner by a physician, in a private room, with both parents present. Physicians should carefully present an informed and balanced view of the condition and should not forget to talk about the positive aspects of DS. They should answer any questions parents might have and provide them with up-to-date printed materials, a list of books, and/or contact information for support organizations and/or parents. It is strongly recommended that physicians and other professionals discuss issues within their specialties and refrain from making judgmental statements or giving their personal opinions on the child’s capabilities and future.

▪ Conduct a comprehensive investigation, focused on studying various aspects of the Lebanese educational system and aimed at developing an action plan to expand the range and number of programs and services in order to meet the country’s demand as well as implement Law 2000/220. This study should have both evaluative and systems change components. In the meantime, LDSA as well as other parent or advocacy associations should gather information about the programs and services currently available, evaluate and monitor their quality, in order to guide parents in their search for appropriate placements. In addition, they could concentrate their fundraising activities on granting scholarships to help needy families pay for appropriate programs and services.

▪ Establish public awareness programs that (1) dispel myths about disabilities, (2) provide up-to-date scientific information about commonly occurring conditions, such as DS, (3) promote
the rights of children with disabilities, (4) demonstrate the etiquette of interacting with individuals with disabilities, and (5) highlight their achievements.

- Empower parents, especially mothers, and self-advocates to advocate for the rights of individuals with disabilities and to involve them in the systems change process. As consumers of special education they are the most important asset for reforming the educational system and building inclusive communities that respect and value diversity.

- Emphasize early intervention to promote the development of each child’s fullest potential.

- Anchor good practices in the culture. Ideologies are deeply rooted in their social-cultural context and may not survive or thrive when transplanted.

- Promote the development of a culture of inclusion. The goal should not just be assimilation into but transformation of the mainstream.

- Define inclusion and specify policies, rules and regulations at the national level. Encourage the Ministry of Social Affairs (MoSA) to subsidize inclusive programs.

- Use curriculum-based and functional assessment instruments instead of relying on culturally-biased assessment instruments to evaluate the abilities and achievement of children with disabilities.

- Use positive behavioral support strategies and refrain from punishing what appears to be maladaptive behavior before analyzing its function for the individual. Functional assessment often reveals that maladaptive behaviors have a communicative function. In those cases, teaching a more adaptive way to communicate that function would not only solve the problem, but would also enhance the individual’s behavioral repertoire.

- Emphasize staff training and continuous professional development.

As briefly noted in Chapter 3, I thoroughly enjoyed interviewing the study’s participants. My reflection on the stories they bravely and openly shared gave me a clear perception of their perspective and had a transformative effect on me. Not being a mother myself, but having been brought up by wonderful parents and an especially devoted, nurturing, and attentive mother, I have always had a lot of respect and admiration for mothers. This study amplified and deepened my respect and admiration for motherhood, particularly mothers’ commitment to their child with DS, their adaptability, their perseverance, their resilience, their strength, and their ability to cope despite the countless problems they face. In addition to (a) the trauma following the birth of their child; (b) the difficulties involved in having to develop new knowledge and skills, reconstruct their ideas of themselves, their values, and their aspirations; (c) the frustrations in facing an intolerant society that marginalizes their child; (d) the trouble involved in learning to deal with a wide range of professionals and agencies and in developing assertive negotiating skills to advocate for their child in order to obtain the best resources; they face frequent challenges that necessitate problem solving strategies and creativity to resolve. They commendably do all of the
above while maintaining a positive hopeful attitude despite the slow progress and the many obstacles and set-backs.

I began this report by quoting Emily Perl Kingsley’s insightful essay about what it is like to have a child with Down syndrome. In order to make a point about the importance of authentically representing someone’s perspective, I am going to conclude it by quoting another insightful essay, which is in line with the empirical findings of this study. It was written by a humorist columnist who adopted a child when she was told it was not possible for her to conceive, but subsequently had two natural children. Although none of her children had a disability, her column “The Special Mother,” which was published in the early eighties, and reprinted in 1983 in her book Motherhood: The second oldest profession rings with the truth of experience and reveals a more authentic insight into the essence of mothering a child with a disability than the professional and research literature of that period, which unfortunately focused only on the psychodynamic and pathological aspects of the process.

Wondering how mothers of children with disabilities were chosen, Erma Bombeck (1983, pp. 70-73) wrote:

> Somehow, I visualize God hovering over Earth selecting His instruments for propagation with great care and deliberation. As He observes, He instructs His angels to take notes in a giant ledger,


> “Rutledge, Carrie, twins. Patron Saint . . . give her Gerard. He's used to profanity.”

Finally, He passes a name to an angel and smiles, “Give her a handicapped child.”

The angel is curious. “Why this one, God? She's so happy.”

> “Exactly,” smiles God. “Could I give a handicapped child a mother who does not know laughter? That would be cruel.”

> “But does she have the patience?” asks the angel.

> “I don't want her to have too much patience, or she will drown in a sea of self-pity and despair. Once the shock and resentment wear off, she'll handle it.”

> “I watched her today. She has that sense of self and independence that are so rare and so necessary in a mother. You see, the child I'm going to give her has its own world. She has to make it live in her world, and that's not going to be easy.”

> “But Lord, I don't think she even believes in you.”

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32 - Erma Bombeck’s essay “The Special Mother” is also posted on several websites, including: (http://www.our-kids.org/Archives/Special_mother.html), (http://www.myspecialkids.com/2009/02/monday-moment-for-down-syndrome-special.html), (http://adventureswithgaby.blog.com/2010/02/01/the-special-mother-by-erma-bombeck/).
God smiles. “No matter, I can fix that. This one is perfect. She has just enough selfishness.”

The angel gasps, “Selfishness? Is that a virtue?”

God nods. “If she can't separate herself from the child occasionally, she’ll never survive. Yes, here is a woman whom I will bless with a child less than perfect. She doesn't realize it yet, but she is to be envied.”

“She will never take for granted a spoken word. She will never consider a step ordinary. When her child says ‘Momma’ for the first time, she will be witness to a miracle and know it. When she describes a tree or a sunset to her blind child, she will see it as few people ever see my creations.”

“I will permit her to see clearly the things I see—ignorance, cruelty, prejudice—and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life because she is doing my work as surely as she is here by my side.”

“And what about her Patron Saint?” asks the angel, his pen poised in the air.

God smiles. “A mirror will suffice.”
APPENDIX A

ETHICAL CONSIDERATIONS

The Human Subjects’ Committee (HSC) of the Institutional Review Board (IRB) at Florida State University, conditionally approved my application for this research study (HSC No. 2009.2651) on May 22, 2009, pending submission of the Arabic and French translations of the Consent Form. I received the HSC formal Memorandum of Approval with the—stamped approved—three language versions of the Consent Form on September 11, 2009.

This appendix includes copies of the (a) HSC conditional and formal approval memoranda, (b) the—stamped approved—three language versions of the Consent Form, and (c) the Lebanese Down Syndrome Association’s letter welcoming the “opportunity to assist in [the] systematic attempt to examine the problem of educating children with Down syndrome in Lebanon from the mothers’ perspective” and consenting to help the researcher in “implementing this much needed research project by providing her with contact information on potential participants who meet the study’s criteria.”

Subject FC approved conditionally
From Human Subjects <humansubjects@magnet.fsu.edu>
Date Friday, May 22, 2009 10:55 am
To rhatoum@mailer.fsu.edu
Human Subjects Application - For Full IRB and Expedited Exempt Review

PI Name: Rima Hatoum
Project Title: Educating Children with Down Syndrome in Lebanon: An Exploratory Study of Urban Mothers’ Perspective
HSC Number: 2009.2651

Your above-referenced project was reviewed by Human Subjects Committee on 5/13/2009 2:00:00 PM. This e-mail is to advise you that the Committee voted to conditionally approve your application, pending the timely submission of the revisions required by the Committee. You will need to submit the revisions and/or information as described below for review in the online system. Make all changes to the application form in CAPS. Rename uploaded files so that the word revised is in the name ex. revisedsmithconsent.doc. Upload two (2) copies of the revised documents inclusive of all revision(s). In one copy, the revisions should be identified in bold or
highlighted to facilitate IRB review. The second copy should be a 'clean' copy. The revisions must be submitted within 60 days or the application will be closed due to lack or responses. If more time is need please contact a staff member.

Once the revisions have been submitted, the Chair of the Human Subjects Committee will review to insure that the revisions required by the Committee have been completed. Once he approves the revisions, you can expect to receive your formal approval notice and approved consent forms, if applicable, via e-mail thereafter. If additional information or revisions are required in order to approve your project, another e-mail will be sent.

Please note that your application has NOT been formally approved, until you timely submit any required revisions, and those revisions have been reviewed and accepted by the Chair, and you have received a formal notice of approval from this office.

Full Committee Review Minutes:
The committee requested the following:
1. Researcher needs either to upload language translations of the consent forms or provide the date when the language translations will be available for submission to the HSC Office.

Subject: Use of Human Subjects in Research - Approval Memorandum
From: Human Subjects <humansubjects@magnet.fsu.edu>
Date: Friday, September 11, 2009 12:25 pm
To: rhatoum@mail.fsu.edu

Office of the Vice President For Research
Human Subjects Committee
Tallahassee, Florida 32306-2742
(850) 644-8673 · FAX (850) 644-4392

RE-APPROVAL MEMORANDUM

Date: 9/11/2009

To: Rima Hatoum

Address: P O Box 16526, Tallahassee, FL 32317-6526
Dept.: SPECIAL EDUCATION & REHABILITATION COUNSELING

From: Thomas L. Jacobson, Chair

Re: Re-approval of Use of Human subjects in Research Educating Children with Down Syndrome in Lebanon: An Exploratory Study of Urban Mothers' Perspective
Your request to continue the research project listed above involving human subjects has been approved by the Human Subjects Committee. If your project has not been completed by 5/12/2010, you are must request renewed approval by the Committee.

If you submitted a proposed consent form with your renewal request, the approved stamped consent form is attached to this re-approval notice. Only the stamped version of the consent form may be used in recruiting of research subjects. You are reminded that any change in protocol for this project must be reviewed and approved by the Committee prior to implementation of the proposed change in the protocol. A protocol change/amendment form is required to be submitted for approval by the Committee. In addition, federal regulations require that the Principal Investigator promptly report in writing, any unanticipated problems or adverse events involving risks to research subjects or others.

By copy of this memorandum, the Chair of your department and/or your major professor are reminded of their responsibility for being informed concerning research projects involving human subjects in their department. They are advised to review the protocols as often as necessary to insure that the project is being conducted in compliance with our institution and with DHHS regulations.

Cc:
HSC No. 2009.2651
استمارة الموافقة

تعليم الأطفال الذين لديهم متلازمة داون في لبنان: دراسة استكشافية حول وجهة نظر الأمّات في المدن

الرجاء الإطلاع على المعلومات التالية لكي تتسنى لك إتخاذ قرار المشاركة في هذه الدراسة البحثيّة. مشاركاتك طوعيّة. وللكمل الحرية أن تتزادي عدم المشاركة أو أن تنسحب في أي وقت كان أثناء البحث.

تهدف هذه الدراسة إلى استكشاف العوامل الأساسية في تعليم الأطفال الذين لديهم متلازمة داون في لبنان من خلال الإطلاع على وجهة نظر الأمّات. الغاية من ذلك تطوير نظرية جوهريّة (substantive theory) العملية التي تضمنها أن تفسر تجارب الأمّات.

هذه دراسة بحثيّة نوعيّة تعتمد منهجية النظرية المجهرة (grounded theory). هذه دراسة بحثيّة نوويّة تعتمد منهجية النظرية المجهرة (grounded theory). الدليل الأولي لتحديد النتائج هو نتائج الأبحاث. نحن نؤمن أن مشاركة الأمّات في تحرير هذا المجال لا تشمل الدراسة أي بيانات رقمية أو تحقيقات إحصائية.

سيتم جمع البيانات من خلال مقابلات من المتوقع أن تدوم بين ثلاث وأربع ساعات. وقد يتطلب هذا أكثر من جلسة.

بالإضافة إلى ذلك، وفقًا للتمكن من التوجه اليدوي، تختلف تقييم التحليل الأولي للنتائج من ناحية قابلية التطبيق.

ستطرح خلال المقابلة أسئلة مفتوحة حول هذا الموضوع (أسئلة بدون خطابات مسبقة) وستسجِل المقابلة صوتيًا من أجل توفير أدوات بديقة. ستكون هذه الأسئلة الابتدائية التي ستستخدم للتحليل والتمثيل لجوانب ماهية داخلية تعليم الأطفال الذين لديهم متلازمة داون في لبنان. ستكون المقابلة متصلة بهذه الدراسة إلى النتائج المتوقعة وتعبر بأكملها عن البيانات في خزانة محفظة الإنترنت في منزل الباحثة. ومن ثم سيتم إتمامها بعد الانتهاء من الدراسة أو مع حلول 10 كانون الأول 2010 كحد أقصى.

من الممكن أن يُقتَرَب تصريح أو أكثر لك حرفيًا في التقرير النهائي. لكن لن يتم الإفصاح عن أي معلومات خاصَّة تُحدد الهوية الشخصيّة. لن يتم برمجة أشكال بيانات البحث بأنواع اقرأ قانونًا. أما الباحثة، فقد كانت ساعد في تأسيس هويتك كمشاركتي. وسيتم بذل كفاءة الجهود للحرص على أن تبقى جميع المعلومات الشخصيّة التي تحصل عليها خلال هذه الدراسة سريّة.

الرجاء عدم التزديد في طرح أي سؤال حول الدراسة، سواء قبل المشاركة أو في خلالها.

كما أنني على استعداد وبكل سرور أن أطلعك على نتائج الدراسة بعد الانتهاء من البحث، في حال رغبتك في ذلك.

FSU Human Subjects Committee approved on 9/11/09 VOID after 5/12/2010
من غير المتوقع أن تكون هناك أية مخاطر، أضرار أو إزعاج له علاقة بالدراسة. كما ستتشمل المناقشة المتوقعة المرتبطة بمشاركتك في هذه الدراسة ما يلي:

- فرصة المشاركة في دراسة بحثية نوعية.
- حرية التعبير عن آرائك، وتجسيد أفكارك وتقاليدها لغير، بالإضافة إلى التعبير عن مشاعرك في بيئة داعمة.
- لا تُطلِق الأحكام.
- تثمين صوتك وفرصة لإسماعك مع أصوات آخرين، لتمثيلهم لمتلازمة داون.
- فرصة المشاركة في صياغة مقارنة عامة حول التعليم الخاص والخدمات المرتبطة به في لبنان من وجهة نظرك كمستفيد لهذه الخدمات.
- إمكانية إحداث تأثير إيجابي على أبحاث السياسات والإجراءات الإجرائية المستقبلية من خلال مساهمتك.

تذكر أن مشاركتك طوعية. ولكل مشاركتك أن تقترن عدم المشاركة أو أن تنسحبي في أي وقت كان أثناء البحث.

الرجاء التوقيع على هذه الاستمارة للتعبير عن موافقتك على المشاركة في البحت المذكور على المعرفة التامة لطبيعة إجراءات الدراسة البحثية ودفعتها. سيتم تزويديك بنسخة خاصة بك عن هذه الاستمارة.

<table>
<thead>
<tr>
<th>تاريخ توقيع المشاركة</th>
<th>تاريخ توقيع البحت</th>
</tr>
</thead>
</table>

في حالة كان لديك أي سؤال بشأن مشاركتك في هذه الدراسة، فرجى الاتصال بي، أنا البحت:

Rima Hatoum
Florida State University, Department of Special Education
mothersperspective@gmail.com أو rhatoum@fsu.edu

في حالة كان لديك أي سؤال حول تصميم البحت، فرجى الاتصال ب忙着ة البحت:

Mary Frances Hanline, Ph. D.
Florida State University, Department of Special Education
mhanline@fsu.edu

(Chair of the Human Subjects Committee) (Chair of the Human Subjects Committee)

(Florida State University) (Florida State University)

(Florida State University) (Florida State University)

(Florida State University) (Florida State University)

(Florida State University) (Florida State University)

((Vice President for the Office of Research) (Vice President for the Office of Research))

(Florida State University) (Florida State University)

من خلال نائب رئيس مكتب البحت (Vice President for the Office of Research) (Vice President for the Office of Research)

على الرقم: 850 (850) أو المراسلة على البريد الإلكتروني: jth5898@fsu.edu

(Chair of the Human Subjects Committee) (Chair of the Human Subjects Committee)

(Florida State University) (Florida State University)

(Florida State University) (Florida State University)

(Florida State University) (Florida State University)

(Florida State University) (Florida State University)

(Vice President for the Office of Research) (Vice President for the Office of Research)

(Florida State University) (Florida State University)

على الرقم: 850 (850) أو المراسلة على البريد الإلكتروني: jth5898@fsu.edu
The following information is provided for you to decide whether you wish to participate in the present research study. Your participation is voluntary. You are free to decide not to participate or to withdraw at any time.

The purpose of this study is to explore critical factors in educating children with Down syndrome in Lebanon by examining mothers’ perspective. The intent is to develop a substantive theory of the dynamics of this process that explains their experience.

This is a grounded theory qualitative research study. Its goal is to understand the phenomenon of educating children with Down syndrome in Lebanon in terms of the meanings mothers ascribe to it and their description of their experience. No numerical data or statistical analyses are involved.

Data will be collected through interviews that are estimated to last about three to four hours. This might require more than one session. In addition, at a later stage, you might be asked to rate the applicability of the researcher’s preliminary analysis of the study’s findings.

The interview will consist of open-ended questions about the topic. It will be digitally audio recorded in order to accurately capture your answers, which are the raw data to be analyzed and interpreted to understand the phenomenon of educating children with Down syndrome in Lebanon. Only the researcher will have access to these recordings. They will be kept in a locked cabinet at her home. They will be destroyed after the completion of the study or by December 10, 2010.

One or more of your statements might be quoted verbatim in the final report. However, no personally identifiable private information will be disclosed. Your name will not be associated with the research findings in any way, and only I, the researcher, will know your identity as a participant. Every effort will be made to ensure that all personally identifiable information obtained during the course of the study will remain confidential.

Do not hesitate to ask any questions about the study either before participating or during the time that you are participating.

If you are interested, I will be happy to share the study’s findings with you after the research is completed.

* The Consent Form will be translated into Arabic and French and printed on both sides of one sheet of paper.

FSU Human Subjects Committee approved on 9/11/09 VOID after 5/12/2010
There are no anticipated risks and/or discomforts associated with the study. The expected benefits associated with your participation in this study include:

- The opportunity to participate in a qualitative research study.
- The personal benefit of expressing your opinions, crystallizing & communicating your thoughts, and venting your feelings in a supportive non-judgmental environment.
- The opportunity to have your voice along with that of other mothers of children with Down syndrome valued and heard.
- The opportunity to participate in formulating an aggregate rounded view of special education and related services in Lebanon from your perspective as consumer of these services.
- The possibility of impacting future research, policy, and practice decisions by contributing to the formulation of the constructed reality of your viewpoint.

Please remember that your participation is voluntary. You are free to decide not to participate or to withdraw at any time.

Please sign this form to express your consent to participate with full knowledge of the nature and purpose of the research study’s procedures. A copy of this consent form will be given to you.

Signature of Participant ____________________________ Date ____________________________

Signature of Researcher __________________________ Date ____________________________

If you have any questions about your participation in this study please contact me, the researcher:

Rima J. Hatoum
Florida State University, Department of Special Education
Beirut Phone Numbers: Home 01-491092 Mobile: 70-356268
Email: rhatoum@fsu.edu or mothersperspective@gmail.com

If you have any questions about the research design, please contact the researcher’s advisor:

Mary Frances Hanline, Ph. D.
Florida State University, Department of Special Education
Email: mhanline@fsu.edu

If you have any questions about your rights as a research participant in this study, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Committee, Institutional Review Board, Florida State University, through the Vice President for the Office of Research at (850) 644-8633, email: jth5898@fsu.edu.
FORMULAIRE DE CONSENTEMENT

L’éducation des enfants porteurs du syndrome de Down au Liban:
Une étude exploratoire de la perspective des mères urbaines

Les informations suivantes vous sont fournies pour que vous décidiez si vous souhaitez participer à cette étude. Votre participation est volontaire. Vous êtes libre de décider de ne pas participer à ce projet de recherche ou de vous en retirer à n’importe quel moment.

Le but de cette étude est d'explorer les facteurs essentiels à l’éducation des enfants porteurs du syndrome de Down au Liban, en examinant la perspective des mères. L’intention est de développer une théorie substantive (substantive theory) de la dynamique de ce processus qui expliquerait leur expérience.

L’objectif de cette recherche qualitative, qui adoptera la méthode de la théorie bien fondée (grounded theory), est de comprendre le phénomène de l’éducation des enfants porteurs du syndrome de Down au Liban sur le plan de la signification que lui attribuent les mères et leur description de leur expérience. Il n'y aura pas de données numériques ou d'analyses statistiques.

Les données seront collectées par le biais d’entretiens qui devraient durer de trois à quatre heures. Cela pourrait nécessiter plus d’une séance. En outre, à un stade ultérieur, vous pourriez être appelée à évaluer l'applicabilité de l'analyse préliminaire de la chercheuse des résultats de l'étude.

L’entretien sera composé de questions à réponses ouvertes sur le sujet. Il sera enregistré en audio numérique afin de noter vos réponses d’une manière précise. Vos réponses sont les données premières qui seront analysées et interprétées afin de comprendre le phénomène de l'éducation des enfants porteurs du syndrome de Down au Liban. Seule la chercheuse aura accès à ces enregistrements. Ils seront gardés dans une armoire fermée à son domicile et seront détruits après la fin de l'étude ou le 10 décembre 2010.

Une ou plusieurs de vos déclarations pourraient être citées à la lettre dans le rapport final. Toutefois, aucune information privée et personnelle ne sera dévoilée. Votre nom ne sera associé aux résultats de la recherche en aucun cas. Seule moi, la chercheuse, connaîtra votre identité en tant que participante. Tout effort sera déployé pour s’assurer que les informations personnelles obtenues dans le cadre de l’étude resteront confidentielles.

N'hésitez pas à poser des questions concernant l'étude, soit avant de participer ou durant votre participation.

Si vous le désirez, je mettrai à votre disposition les résultats de l’étude après la fin de la recherche.

FSU Human Subjects Committee approved on 9/11/09 VOID after 5/12/2010
Aucun risque et/ou inconfort pour vous, associés à votre participation à cette étude, ne sont prévus. Les avantages de votre participation à cette étude comprennent:

- L'occasion de participer à une étude de recherche qualitative.
- Le profit personnel d'exprimer vos opinions, de préciser et de communiquer vos pensées et vos sentiments dans un environnement soutenant et sans jugements.
- L'occasion de valoriser et de faire entendre votre voix jointe à celle d'autres mères d'enfants porteurs du syndrome de Down.
- L'occasion de participer à la réflexion d'une vision générale de l'éducation spécialisée et des services qui y sont liés au Liban à partir de votre perspective en tant que bénéiciaire de ces services.
- La possibilité d'influer les décisions de pratique, les politiques, et les recherches à l'avenir en contribuant à la formulation de la réalité (constructed reality) de votre point de vue.

Veuillez vous rappeler que votre participation est volontaire. Vous êtes libre de décider de ne pas participer à ce projet de recherche ou de vous en retirer à n'importe quel moment.

Veuillez signer ce formulaire pour exprimer votre consentement à participer en toute connaissance de la nature et de l'objectif des procédures de ce projet de recherche. Une copie de ce formulaire de consentement vous sera remise.

Signature de la Participante __________________________  Date __________________________

Signature de la Chercheuse __________________________  Date __________________________

Si vous avez des questions concernant votre participation à cette étude, veuillez me contacter, la chercheuse:

Rima J. Hatoum
Florida State University, Department of Special Education
Téléphones à Beyrouth: Domicile: 01-491092   Cellulaire: 70-356268
Courriel: rhatoum@fsu.edu ou mothersperspective@gmail.com

Si vous avez des questions concernant la conception de la recherche, veuillez contacter la conseillère de la chercheuse:

Mary Frances Hanline, Ph. D.
Florida State University, Department of Special Education
Courriel: mhanline@fsu.edu

Si vous avez des questions concernant vos droits en tant que participante à cette étude, ou si vous pensez avoir été exposée à des risques, vous pouvez contacter le Président du Comité des Participants Humains (Chair of the Human Subjects Committee), Conseil de Revue Institutionnelle (Institutional Review Board), Université de L'État de Floride (Florida State University), par l'intermédiaire du Vice Président du Bureau de la Recherche au (850) 644-8633, courriel: jth5898@fsu.edu.

FSU Human Subjects Committee approved on 9/11/09 VOID after 5/12/2010
Beirut, June 23, 2005

John Tomkowiak, M.D.
Chair, Human Subjects Committee
Institutional Review Board (IRB)
Office of Research
Florida State University
john.tomkowiak@med.fsu.edu

Dear Dr. Tomkowiak:

We have been aware for some time of Rima J. Hatoum’s intent to conduct a research study to explore critical factors in educating children with Down syndrome in Lebanon by examining mothers’ perspective. She recently provided us with an abstract of the proposed study ["Educating Children with Down Syndrome in Lebanon: An Exploratory Study of Urban Mothers’ Perspective"], specifying its purpose and methodology, that we discussed at one of our executive board meetings.

We are writing this letter to express the Lebanese Down Syndrome Association’s (LDSA) consent to help her in implementing this much needed research project by providing her with contact information on potential participants who meet the study’s criteria. This information could be obtained from LDSA’s membership database or from other sources at our disposal. We understand that participation in the proposed study is voluntary, that the potential participants we identify are free to decide not to participate or to withdraw at any time, and that no incentives or penalties will be used to influence their decision. We also understand that in order to preserve the anonymity of participants and the confidentiality of the information they share, the researcher [Rima J. Hatoum] will be the only person to know the identity of the mothers who choose to participate in the study.

We welcome this opportunity to assist in this systematic attempt to examine the problem of educating children with Down syndrome in Lebanon from the mothers’ perspective and we look forward to using the insights gained to guide our advocacy efforts.

Sincerely,

Fadia Farah, President

cc: Jeanne Flannery, Ph. D, Primary Reviewer jflanner@mailer.fsu.edu
   Julie Haltiwanger, Secretary to IRB jth5898@garnet.acns.fsu.edu
   Rima J. Hatoum, Researcher rhatoum@mailer.fsu.edu
**APPENDIX B**

**BACKGROUND INFORMATION ABOUT CHILD & FAMILY***

Information about Child with Down Syndrome

<table>
<thead>
<tr>
<th>Name:</th>
<th>D.O.B:</th>
<th>Age:</th>
</tr>
</thead>
</table>

**Characteristics**
- Vision
- Hearing
- Speech/Communication
- Receptive language(s)
- Expressive language(s)
- Behavior (self control & discipline)
- Social skills
- Independence/self-reliance skills
- Likes/dislikes

**Medical/Health Concerns**
- Congenital heart defect
- Gastrointestinal
- Childhood Leukemia
- Thyroid
- Respiratory
- Other

**Physical concerns**
- AAI
- Obesity
- Other

**Current Programs & Services (if any)**

*Questions about the child with Down syndrome and his family were asked in an open-ended manner to gather information listed on this form. The form is organized to facilitate note-taking by the researcher. It was not shown to participants in order to prevent the categories listed on it from contaminating their conceptualization of the type of programs and services their child receives.*
<table>
<thead>
<tr>
<th>Educational Programs</th>
<th>Related Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early intervention (Birth to 3)</td>
<td>Diagnosis and evaluation</td>
</tr>
<tr>
<td></td>
<td>Medical and health</td>
</tr>
<tr>
<td>Preschool (Ages 3-5)</td>
<td>Speech-language and audiology</td>
</tr>
<tr>
<td></td>
<td>Physical and occupational</td>
</tr>
<tr>
<td>Education (Ages 5-21)</td>
<td>Psychological and behavioral</td>
</tr>
<tr>
<td></td>
<td>Vocational</td>
</tr>
<tr>
<td>Vocational Training</td>
<td>Recreational</td>
</tr>
<tr>
<td></td>
<td>Community living</td>
</tr>
<tr>
<td>Adult Education</td>
<td>Social work</td>
</tr>
<tr>
<td></td>
<td>Parent counseling and training</td>
</tr>
<tr>
<td>Other</td>
<td>Other</td>
</tr>
</tbody>
</table>
Information about Child’s Family

Number of Siblings:     Birth Order:

Mother’s Level of Educational Achievement
Mother’s Occupation
Mother’s Current Employment

Father’s Level of Educational Achievement
Father’s Occupation
Father’s Current Employment

Socio-Economic Status

Parents’ Marital Status
Family Structure (nuclear/extended)
Significant Others with Whom Child Interacts/Spends Time Daily.

Family’s Ethnicity
Family’s Religious Affiliation/Sect
APPENDIX C

INTERVIEW QUESTIONS

Individual, face-to-face, semi-structured, long qualitative interviews using open-ended questions were conducted with the study’s participants. In qualitative research, interview questions cannot be predetermined before the study begins. They evolve as the researcher is sensitized to the meanings that the participants bring and become more focused as themes emerge. The set of questions presented below, cluster around four issues related to the phenomenon explored in this study. They served as a map of the territory being explored. They were useful in facilitating interviewing when I employed them (a) as a point of departure for collecting empirical materials, or (b) as a guide for interviewing participants who were not very articulate or those who required prompting to reconstruct their experience. However, these questions were not used verbatim or in the order they appear on the form. In addition, they were refined, supplemented, or discarded as needed during the interviewing process.

Mother’s View of Her Child with Down Syndrome

Describe your child

How did you learn about your child’s condition?

What was your reaction to the news?

What was the reaction of significant others (husband, siblings, extended family, friends) to the news?

What are your child’s strengths?

What are your child’s limitations?

What are your child’s rights?

What are your dreams for your child?
What are your concerns about your child?

What do you foresee your child’s future to be like?

Have your views about your child changed over time?

What would you like people to know about persons with Down syndrome?

**Mother’s Experience with and Views about Obtaining Educational Programs and Services**

What made you realize that you needed help to support your child’s development?

Describe what you went through to identify your child’s needs and to locate appropriate programs and services.

If you were unable to obtain programs and services for your child, describe your experience.

  What do you think/feel about your experience?

  What were the major reasons why you were unable to obtain programs and services?

  What hindered the process of getting programs and services?

  What, in your opinion, could have facilitated the process?

If you obtained programs and services for your child, how did you obtain them? Describe your experience.

  What do you think/feel about your experience?

  What helped the process of getting programs and services?

  What hindered the process of getting programs and services?

  What, in your opinion, could have facilitated the process?

What programs and services is your child receiving currently?

What programs and services has your child received previously?

  Describe each program and each service
What do you think of/how do you feel about the program or service?

How is/was the program or service helpful for your child’s development?

What other programs or services do you think your child needs, should have gotten, or should be getting?

**Mother’s Knowledge of and Views about**

**Appropriate Educational Programs and Services**

What would be the ideal mix of programs and services for your child?

What should programs and services teach or support your child in to promote optimal development of potential?

Visualize the ideal mix of programs and services you think should be available to promote your child’s optimal development. How would they approach the following issues?

- Assessment and admission procedures
- Placement setting
- Goals
- Curriculum
- Professional services
- Support services
- Outcomes
- Etc.

What would be ideal to facilitate the process of educating your child?

What do you know about programs and services for children with Down syndrome in other countries?

How do these programs compare with those available in Lebanon?

Would such programs be beneficial to your child?

What aspects of programs and services in other countries would you have liked to have available in Lebanon?
What information about Down syndrome as well as programs and services for your child would you like to receive? What is your preferred format for receiving that information? (Verbal exchange with other parents, print, training, videotapes, etc).

Mother’s Perceived Role and Desired Role in Educating Her Child with Down Syndrome.

In what ways, if any, are you involved in your child’s programs and services? Describe your current role.

How involved do you think you should be in your child’s education?

How involved would you like to be in your child’s programs and services? Describe the role you would like to have.

What support services for yourself did you receive in the past or are receiving now? What do you think of / how do you feel about these services? What support services for yourself do you wish you could receive?

Summary

What helped you the most?

What obstacles frustrated or hindered you the most?

How has this experience changed you?

Would you have preferred to avoid this experience?
APPENDIX D

VALIDATION OF FINDINGS

Please read the attached findings of the qualitative study “Educating Children with Down Syndrome in Lebanon: An Exploratory Study of Urban Mothers’ Perspective,” rate them from one to ten on the following three dimensions using the scale below, and add your comments. Thank you for your cooperation.

Strongly Disagree 1------2------3------4------5------6------7------8------9------10 Strongly Agree

1. **This qualitative study’s findings are credible**
   A qualitative study’s findings are credible when they present “such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it from those descriptions or interpretations as their own.”(Sandelowski, 1986, p. 30).

   Rating:
   Comments:

2. **This qualitative study’s findings are applicable**
   Do these findings fit into contexts outside the current study? Are they meaningful and applicable to your own experience?

   Rating:
   Comments:

3. **This qualitative study’s findings reflect a balanced view of all perspectives, values, and beliefs on the subject**

   Rating:
   Comments:
REFERENCES


- Disabled little girl forbidden to enter beach resort, July 10, 2004.
- The case of the little girl Noor referred to National Committee on Disability Affairs, July 13, 2004
- Family Planning Association’s solidarity with Noor, July 14, 2004.


132
 Beach resort refuses to admit a little girl because she is “disabled”, July 9, 2004.
 Ministry of Social Affairs refers disabled girl’s case to the National Committee on Disability Affairs, July 13, 2004.


- Fatah-al Islam took up again Israel’s dirty work, July 13, 2007.
- Siniora reviews successes of outgoing cabinet, November 17, 2007.
- Lebanon’s precarious and unpredictable political situation, November 17, 2007.


EHA (1975). Education of All Handicapped Children Act, Public Law 94-142 [In 1975, Congress passed Public Law 94-142, now known as IDEA (Individuals with Disabilities Education Improvement Act of 2004)].


Inclusion Network (2004). Grant proposal submitted in response to a Council for Development and Reconstruction request for proposals (CDR RPF#: CDP/TH-2) for a two-year project to promote inclusive practices for individuals with disabilities in Lebanon (Funded in May 2004 through a loan from the International Bank for Reconstruction and Development--World Bank).


Lakkis, S. (2004, June 15). Rescuing disabled people from poverty and marginalization [Press release in English received through personal (email) communication with Ms. Sylvana Lakkis, president of LPHU].


NDSC – National Down Syndrome Congress, 1370 Center Drive, Suite 102, Atlanta, GA 30338, 770.604.9500; 800.232.6372, info@ndsccenter.org, http://www.ndsccenter.org.


M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability*, (pp. 221-238). Baltimore: Brookes.


http://www.unesco.org/education/pdf/SALAMA_E.PDF.


Rima J. Hatoum was awarded the 2009 UNESCO/Emir Jaber al-Ahmad al-Jaber al-Sabah Prize to Promote Quality Education for Persons with Intellectual Disabilities, on December 8, 2009. She is a professional in the field of disabilities with expertise in the areas of assessment, curriculum development, positive behavioral support, inclusive education, teacher training, and research. Her degrees include: BA in Psychology, Teaching Diploma in Elementary Education, MA in Guidance and Counseling—all from the American University of Beirut, Lebanon. She is qualified to teach children with intellectual, emotional, physical, or visual disabilities as well as children with severe multiple disabilities or chronic illnesses. She is also certified in Applied Behavior Analysis and is a charter member of the Florida Positive Behavioral Support State Training Team. She has been engaged in teaching, program development, teacher training, research, and consulting in the field of disabilities for over 30 years. Her experience includes:

- **Classroom Teaching**: She taught students without disabilities as well as students with various disabilities at all levels in private and public schools as well as in institutional and forensic settings for 10 years, in three different countries (Lebanon, UK, and USA).

- **Program Development**: As a Program Specialist at the Florida Department of Education (DOE), Bureau of Education for Exceptional Students (BEES) for 8 years, she was responsible for providing technical assistance and monitoring statewide programs that included the following:
  
  - Programs for students with severe or profound disabilities (severe intellectual disabilities, autism spectrum disorders, dual sensory impairments, multiple disabilities) with emphasis on inclusion, quality of life issues, developing functional skills, and positive behavioral support.
  
  - Programs for students who are homebound or hospitalized due to acute or chronic illnesses with emphasis on providing the least restrictive service delivery methods for students who are chronically ill, medically fragile, or technology dependent.
  
  - Educational programs provided to students with disabilities by State agencies other than the Florida Department of Education, mainly programs operated or supported by the Florida Department of Health and Rehabilitative Services.
- Programs for exceptional students with Limited English Proficiency.

- Adaptive Physical Education Programs.

- **Teacher Training:** She taught university courses in special education and supervised practicum students as well as student teachers (interns) working with students with low incidence or high incidence disabilities at all levels. As part of her duties at DOE/BEES and later as a free-lance consultant for UNESCO and other international agencies operating in the Middle East as well as for Lebanese Non-Governmental Organizations, she designed and implemented in-service training programs to prepare teachers to include students with disabilities in their classrooms. These comprised in-service training programs in Lebanon (all disabilities), Syria (visual impairments), and Yemen (all disabilities).

- **Training Resources Development:** She participated in and coordinated the development, field testing, revising, and finalizing of (a) a series of five in-service training manuals on educating children with severe or profound disabilities and (b) a series of 16 research-based modules on community-referenced positive behavioral support for persons with disabilities.

She maintains a global view of disability issues and her work is motivated by a strong commitment to (a) children’s rights, (b) the promotion of inclusive communities through advocacy, education, and research, and (c) the development of equitable systems of service delivery and support that enhance the quality of life of people with disabilities and that are built on self-advocates’ and parents’ perspectives.