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The Impact on Mothers of Raising a Child with Significant Disabilities in the Developing World  

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“The Impact on Mothers of Raising a Child with Significant Disabilities in the Developing World”

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This study is a literature review of 39 articles from the developing world that dealt directly or indirectly with the impact on mothers of raising a child with significant disabilities. Although much research has been done on this topic in North America, Europe and Oceania, comparatively little has been done in the developing world, and only one study had compared mothers’ situation across cultures. Therefore, this study aimed to do just that. The second research aim was to see if John Friedmann’s model of social (dis)empowerment could be helpful and adequate to shed light on these mothers’ situations. The findings were that, although there are slight differences between cultures regarding mothers’ experiences in raising a child with significant disabilities, by and large, their lives were strikingly similar. These mothers did indeed experience disempowerment in the eight bases of social power that Friedmann identified, particularly in the area of “instruments of work and livelihood.” For mothers raising children with significant disabilities, the most important instruments of work and livelihood are their physical bodies and minds, both of which are often compromised in their demanding caregiving role. Although Friedmann’s model was helpful, it was not sufficient to explain these mothers’ situations. For instance, it was found that cultural attitudes and beliefs surrounding disability—which are largely negative—contribute greatly to mothers’ disempowerment in the developing world.

Key Words: developing world, disability, Friedmann, mothers, social disempowerment
### List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AAIDD</td>
<td>American Association of Intellectual and Developmental Disabilities</td>
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<tr>
<td>CBR</td>
<td>Community Based Rehabilitation</td>
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<tr>
<td>CSU-N</td>
<td>California State University-Northridge</td>
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<tr>
<td>HDI</td>
<td>Human Development Index</td>
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<td>SEN</td>
<td>Special Education Needs</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Chapter 1: Introduction

With a global population of close to seven billion, estimates suggest that there are approximately one billion people with a disability in the world today. As populations worldwide are living longer, and as chronic diseases such as cancer and diabetes are increasing even in the developing world, the prevalence of disability will also continue to rise (WHO-WB, 2011, p. xi). Children and adolescents constitute 200 million of those with disabilities (about 10% of the world’s youth), and about 80% of these live in the developing world and experience physical, sensory, intellectual or mental disabilities (United Nations Disability Fact Sheet, 2006 as cited in UNICEF, 2007, p. 3). In addition, 93 million children aged 0-14 in the world have moderate to severe disabilities (WHO-WB, 2011, p. 36).

With these kinds of statistics, it is surprising that disability issues have received so little attention in development efforts (Albert, 2004, p. 13), especially where children are concerned. In fact, many aid organizations still do not have a disability policy in place (Lord et al., 2010; Parnes, 2008). Among those governments and NGOs that do have such a policy, much empty rhetoric fills the pages (Albert, 2004, pp. 8-13). As a result, when disability projects are carried out, they tend to be small, uncoordinated and unsustainable (ibid, p. 12-13). It is clear, therefore, that mainstreaming disability into development cooperation efforts has a long way to go. This is even more surprising given the strong link between disability and poverty (Braithwaite and Mont, 2009). Among children with disabilities in developing countries, those with moderate to severe disabilities are the poorest of the poor. This is because they are the ones most likely to: be shunned by society and even family (resulting in poor social networks), be denied an education (or

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1 Saetermoe et al. (2004) note that disability rates tend to be higher in the developing world because of malnutrition, less access to safe drinking water, inadequate sanitation, poor health care and a lack of rehabilitation services (p. 1032).
2 It is hard to say exactly how much needs to be done, as statistics on efforts to mainstream disability into development cooperation do not appear to exist.
3 Moderate to severe disabilities are those in which a person needs extensive assistance in the tasks of daily living. Those with moderate disabilities would likely need some assistance with mobility, eating and hygiene activities, while those with severe/profound disabilities would certainly need help with all of these things (and would likely require a full-time caregiver). The classification system being used is the DSM-IV-TR, which grades intellectual disability into four categories: mild, moderate, severe and profound. Note that for the purposes of this paper, only the situation of mothers raising children with moderate to severe or profound disabilities (in other words “significant” disabilities) will be explored.
fail once enrolled, due to a lack of assistive devices and special education teachers), be
denied eventual employment due to said lack of education and attitudinal barriers, and be
given lower priority in healthcare than so called “normal” children, or children with only
minor disabilities (Zinkin and McConachie, 1995).

If these children are the poorest of the poor, so too are their mothers. In the past few
decades, development scholars and practitioners have become increasingly cognizant of
the fact that women play a crucial role in a country’s development. Although they are
often poorer than men and more deprived in terms of education and health care, women
hold the keys to the future, as they are primarily responsible for bringing-up the next
generation. Indeed, studies have shown that mothers invest more of their energy and
resources (including more of their disposable income) than fathers to ensure their
children’s wellbeing. They are also primarily responsible for transmitting positive values
and behaviors to their children (Todaro and Smith, 2009, p. 22). If development funds
and initiatives can increasingly go towards advancing: education and health-care for
women, income-generating schemes and integration into the economic mainstream and
women’s freedoms and rights, this will strongly benefit their children (ibid, pp. 22, 340-
341). Indeed, studies have shown that the healthier and more educated a mother is, the
more she will be able to make informed, healthy decisions for her children (and pass
along what she has learned to the next generation) (Glewwe, 2009, p. 124). Therefore,
mothers help to pull their children up out of poverty, reducing the country’s poverty in
the long run (Becker, 1995).

What happens, however, to the mother who is raising a child with a significant disability,
particularly an intellectual one? Indeed, more often than not, a dependent child becomes a
dependent adult, short-term care giving becomes a lifelong responsibility (often hindering
the mother’s ability to find employment), and the child does not learn from the mother’s
better education or health status. Regarding those with significant physical and/or sensory
disabilities, in the developed world it is recognized that with the right supports, these
children have a better chance to eventually live fairly independent lives and may
contribute economically and socially to society. In many developing countries however,
this is not the case. This group—along with the intellectually disabled—are often denied
the right to basic education and health care; therefore, they lose the chance to become
independent (Zinkin and McConachie, 1995). Even if their mothers could access health care, the necessary treatments would be much more costly than interventions needed for children with minor disabilities.

For the above reasons, having a child with significant disabilities often leads to mothers experiencing multiple dimensions of poverty, causing them to go deeper into poverty, and making it likely that they will never escape impoverished living (Park et al., 2002). In addition, not only are mothers expected to be the primary care-giver for the child with a disability, they still have to fulfill their other roles that accompany being a wife and mother (i.e., rearing other children, taking care of extended relatives, finding additional income, etc.) Add to this the fact that many women have to face the stigma, myths and stereotypes that accompany disability in many developing countries, and one can see that such women lead challenging lives indeed (Edwardraj et al., 2010). It is important to make sure that their voices are being heard and their needs are being met. Hence, this research will focus on their unique experiences, needs and opinions, and on what can be done to help reduce their poverty.

1.1 Previous Relevant Research and Current Research Gap

Much research has been done in North America, Western Europe and Oceania on the impact on mothers (or parents in general) of raising children with disabilities in the developed world. These studies tend to focus on one or more of the following factors: financial difficulties (Emerson et al., 2010, UK), stress levels (Wulffaert et al., 2010, Netherlands), parents’ emotions (Van Der Veek et al., 2009, Netherlands; Hoare et al., 1998, UK), psychological well being and social supports (Skok et al., 2006, Australia), quality of life surveys (Weigl et al., 2005, Germany), the positive impacts on the family (Stainton and Besser, 1998, Greer et al., 2006, Ireland), single mothers’ experiences (Cigno and Burke, 1997, UK), immigrant mothers’ experiences (Hatton and Emerson, 2009, UK; Hughes et al., 2008; Daudji et al., 2011, Canada), the sadness and joys that the family experience (Trute et al., 2007, Canada), psychological coping and family adjustment (ibid, 2010, Canada), and spirituality’s role in caregiving (Speraw, 2006, USA).
In other parts of the developed world, research focused on: maternal coping strategies (Mak and Ho, 2006, Hong Kong), parental adaption and satisfaction (Dukmak, 2009, United Arab Emirates), the connection between stress, social supports and well-being (Duvdevany and Abboud, 2003, Israel), caregiver burden (Oh and Lee, 2009, South Korea) and the overall experience of mothers (Lam and Mackenzie, 2002, Hong Kong). These are just some of the hundreds of studies that have been done in the developed world, and they generally evidence the disempowerment that many mothers experience in raising a child with significant disabilities. In comparison, the developing world literature is sparse (Blacher and Mink, 2004).

Over the past decade, about three-dozen studies have, directly or indirectly, taken up the topic of mothers’ perceptions of raising children with significant disabilities in the developing world—particularly in Asia. Therefore, some progress has been made. However, a significant gap in the research to date is that only one study has attempted to make cross-cultural comparisons (between mothers’ experiences in Taiwan, Jordan and Northern Ireland) (McConkey et al., 2008). Note that McConkey et al.’s study includes only one developing country, Jordan.

1.2 Aim of Study

Instead of adding to the increasingly abundant field studies done in the developing world on this topic, and considering that no one has, of yet, compared any of the existing developing country studies, the primary goal of my research is to do just that. Therefore, I will do a structured, focused comparative case study. The overall aim is to increase our knowledge and understanding of these mothers’ situations—to realize the impact on their lives of raising a child with moderate to severe disabilities—by looking across cultures at the commonalities and trends in their experiences. This aim is not an end in itself but a means to more accurately channel development efforts to mothers’ areas of greatest need. By doing so, hopefully their poverty can be alleviated—these mothers who often have the least social power in the developing world.

4 In addition to this, Diken (2006) did a brief literature review on parental perceptions on raising a child with disabilities across cultures. He examined the experiences of Mexican-American, Chinese-American, Arab and Jewish parents. Neither Diken or McConkey et al.’s studies look at the developing world only however.
1.3 Research Questions

The research questions and data comparisons will be guided by Friedmann’s model of social disempowerment. This is important, because no other researcher has attempted to see if mothers’ situations can be understood and analyzed in light of Friedmann’s model. From a cursory reading, however, the model looks quite appropriate as an analytical tool. Friedmann views poverty as a lack of social power in several spheres, having a lack of access to things (bases of social power) that make life full and meaningful for most. The eight bases of social power that he identified were: 1) financial resources, 2) social networks, 3) surplus time over subsistence requirements (free time), 4) social organizations, 5) instruments of work and livelihood (i.e., health), 6) appropriate information, 7) knowledge/skills, and 8) defensible life space. The degree of poverty can be assessed by the overall extent to which families have not gained access to these bases of social power (Freidmann, 1992, pp. 66-67). See chapter 4 for a detailed description of Friedmann’s model.

My research questions are arranged according to Friedmann’s eight bases of social power, and are as follows: In raising a child with a significant disability, what has been the impact on mothers lives in terms of their:

1) ability to work and earn an income (financial resources)
2) ability to socialize and have meaningful relationships (social networks)
3) ability to have free time (surplus time)
4) ability to participate in organizations and functions outside the home (social organization)
5) ability to maintain their own health (physical, emotional, spiritual, etc.) (instruments of work and livelihood)
6) ability to make informed decisions for their child with disabilities (appropriate information)
7) ability for ensure that everyone in the household has a chance to improve their knowledge and skills (knowledge and skills—human capital)
8) ability to continue living in their home (defensible life space)

Note that, in the course of this study, if significant data exists that cannot be grouped under one of the above eight bases of social power (i.e., if Friedmann’s model is not sufficient to explain the data), a new category may be developed.
1.4 Methodology and Limits of Study

As aforementioned, I decided to do a comparative-analytical literature review of 39 studies done in the developing world. Over three-dozen field studies have already been conducted, directly or indirectly, on mothers’ experiences in raising a child with disabilities. However, no researcher has—as of yet—systematically compared, categorized and evaluated the research done so far.

In terms of practicalities, 39 articles were chosen for analysis from the developing world, after doing an extensive electronic database search for appropriate scholarly articles. I had several inclusion criteria to decide which articles to use. The chosen articles: 1) were either qualitative or quantitative in nature and peer-reviewed 2) had mothers as a respondent group, 3) focused on mothers raising children or adolescents with moderate to severe disabilities, 4) took place in the developing world, and 5) had a focus on children/adolescents living at home. After the articles were chosen and read, I started the coding process by searching for quotes and discussions that helped to answer each of the research questions based on Friedmann’s model.

As for the limitations of this study, some of them include: the inherent dangers of cross-cultural comparisons (such as simplifications and generalizations), the existing articles in the developing world being heavily weighted towards Asia (reason unknown), the children’s voices themselves not being captured, and the fact that some studies did not indicate the socioeconomic status of the participating mothers. For more details, see the methodology section (5.5).

1.5 Significance of Study and Ethical Considerations

Aside from the strongest contribution of this study: being the first to compare a significant number of studies in the developing world on this topic), and the analytical contribution (seeing if Friedmann’s model can shed light on these mothers’ situations),

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5 An example of indirect information about mothers’ experiences is when the article’s topic is, for example, about the importance of parent-to-parent support groups for mothers, and in the context of such an article, mothers discuss their challenges in raising a child with significant disabilities.
there are other merits of such research. For instance, Chang and McConkey (2008, p. 27) note:

A study of the same phenomena across different cultures, such as parenting a child with an intellectual disability, enriches our understanding of a shared experience and accrues greater insights into the diversity of responses that humans make to different situations and of the influences that may determine their reactions.

In addition, areas of possible future research will be identified based on common identified needs in the studies, or from contradictory data that needs clarification, and this can then form the basis of future field studies. Furthermore, if we learn where mothers are struggling the most in raising these children (i.e., what keeps them impoverished), we will be able to focus development efforts and funds in their areas of greatest need. In this way, the most vulnerable children may also have a chance to lessen their poverty and a lead a dignified life.

Some may question whether it is “worth while” to spend already scarce development funds on children with disabilities and their families. After all, to construct one school with the adaptations necessary to accommodate students with high special needs, several regular schools could have been constructed for roughly the same price in any number of developing countries. This is truly an ethical and humanitarian dilemma, particularly where those with significant intellectual disabilities are concerned. For this group, there may not be much visible “improvement,” even if the best education and therapies are provided at great cost (much investment with seemingly little return). Indeed, they may not be able to “give back” to society in ways deemed valuable by most (i.e., economically). Therefore, some may consider it a waste to spend limited funding on children with disabilities, particularly those with moderate to severe disabilities. However, even though these children and their mothers do not represent the majority of the world’s poor, they are arguably the poorest of the poor, and therefore warrant both development attention and compassion.

Finally, determining one’s contribution to society should not be based solely on earning potential and social acumen, but on how much joy and life this person can bring to others and to the world. Literary accounts have shown that those with intellectual disabilities particularly have enormous potential to bring people together, and they often have unique
insights and creativity that are unrivaled (Vanier, 2009). As much as the literature depicts mothers struggling to cope with raising a child with profound disabilities, it also captures moments of great joy in their lives together (Greer, 2006; Dukmak, 2009).

1.6 Disposition of the Paper
In the rest of the paper, chapter 2 defines key terms, concepts and describes the various models of disability that have guided disability thought and practice over the years. Chapter 3 explains why disability issues have been low on the development radar and why this is problematic. Chapters 4 and 5 deal with the analytical framework chosen to guide the analysis (Friedmann’s social disempowerment model) and methodological issues, while chapters 6 and 7 present the findings, analysis, conclusions and directions for future research.
Chapter 2: Key Terms, Concepts and Disability Models

This chapter introduces key terms, concepts and describes the various models of disability that have guided disability thought and practice over the years. It is particularly important to review disability-related terminology, as these terms will be referred to throughout the paper.

2.1 Disability

The World Health Organization (WHO) notes that disabilities can be intellectual, developmental, physical, sensory or mental in nature. The term “disability” is an overarching term that describes activity limitations, impairments and participation restrictions:

An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives (WHO-Disabilities, 2011).

2.2 Physical and Sensory Disabilities

A physical disability is a bodily impairment that hinders the movement capacity of one or more limbs, or impacts gross or fine motor ability. A physical disability can also include impairments that make activities of daily living difficult (such as a respiratory illness or epilepsy). A sensory disability, on the other hand, impacts one of the five senses (CSU-N, 2008). If severe, physical and sensory disabilities can limit the activities one does and can therefore lessen his/her general level of participation in society if adaptations are not made (both individual and societal adaptations) (WHO-Disabilities, 2011).

2.3 Intellectual and Developmental Disabilities

Intellectual disability is a specific branch of disabilities that significantly and adversely impacts cognitive functioning (i.e., in the areas of learning, reasoning and problem solving). It also hinders adaptive behavior in practical, social and conceptual realms. Signs and symptoms of intellectual disability always emerge before the age of 18, but are often noticeable much earlier (AAIDD, 2011). Intellectual disabilities are grouped in order of severity: minor, moderate, severe and profound. Those with profound intellectual

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6 Disabilities can also overlap. For instance, cerebral palsy often includes elements of intellectual and physical disabilities.
7 However, it usually refers to full or partial loss of hearing or sight.
disabilities typically score under 20 in the Intelligence Quotient Scale (Pawlyn and Carnaby, 2008). Intellectual disability is often synonymous with mental retardation, but due to the taboo surrounding that term in many English-speaking countries, “intellectual disability” and “developmental disability” are the terms that have come to replace it in common usage. Unfortunately, many medical lexicons continue to use the term “mental retardation,” defining it as a cognitive impairment that results in a score of 70 or less on the Intelligence Quotient Scale.8

In contrast to intellectual disability, “developmental disability” is a term more widely used in North America. It is seen by many as synonymous with intellectual disability, however, there are a few differences. First of all, “developmental disability” is an overarching term that includes both intellectual and physical disabilities. As the AAIDD (FAQ, 2011) notes:

Some developmental disabilities can be strictly physical, such as blindness from birth. Some individuals have both physical and intellectual disabilities stemming from genetic or other physical causes (e.g., Down Syndrome, fetal alcohol syndrome). Sometimes intellectual disabilities can stem from nonphysical causes, such as the level of child stimulation and adult responsiveness.

2.4 Models of Disability
The first model of disability was the medical model. It regarded disability as something wrong that needed to be fixed or cured, so that people with disabilities could lead more “normal” lives and adjust themselves to the way society works (UNICEF, 2008, p. 21). This model thus implies that it is the person with a disability who must change and adapt in order to fit into society. Medical treatments and therapies are the primary means of effecting change (ibid, p. 21; WHO, 2002, p. 8).

The social model of disability emerged as an idea to challenge the medical model in the mid 70s (Oliver and Sapey, 2006).9 It argued that it is society that disables an individual,

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8 Last year, the American Association on Intellectual and Developmental Disabilities formally proposed (in its 2010 edition of Mental Retardation: Definition, Classification and Systems of Supports) that “mental retardation” be universally replaced by “intellectual disability” (AAIDD, 2011). In fact, in October of 2010, Barack Obama signed legislation that this change would be made in all government documents, after a bill entitled Rosa’s Law was unanimously passed by Congress.

9 However, it was only labeled in 1983 as a model in its own right.
not the impairment itself. **10** Proponents of this model contend that societal barriers (i.e., negative attitudes, reluctance to make buildings fully accessible, intentional or unintentional devaluing of someone with an impairment, etc.) are the real disability-causing agents (UNICEF, 2008, p. 22).

The WHO, critical of both models, came-up with ICF (*International Classification of Functioning, Disability and Health*) in 2001, which was based on the biopsychosocial model of the 1970s created by psychiatrist, George Engel. As its name implies, the model focuses on the combination of biological, psychological and social factors that contribute to health and wellness, or the lack thereof (Engel, 1977). Hence, the ICF classification system of health and disability merges the best aspects of both models (and so does not make the mistake of simplifying disability by relegating causation to either the biological or social spheres). **11**

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**10** In other words, a person may have a physical, intellectual or mental impairment but this, in and of itself, does not render a person disabled.

**11** Indeed, the WHO argued that the social model of disability was not realistic in that it largely ignored the biological nature of disability (that impairments do—along with societal factors—contribute to disability). It also recognized that the medical model was inadequate, as it largely saw people with disabilities as needing to be fixed to conform to societal norms (WHO, 2002, pp. 8-9).
Chapter 3. Disability and Development

This chapter explains why disability issues have been low on the development radar and why this is problematic.

In terms of development, disability issues tend to be at the bottom of many NGO and government agendas. This is problematic, since over 80% of the world’s disabled population lives in the developing world (between 500-520 million people) (UN Enable, 2011). Bill Albert, in his study on disability and the development agenda, concluded that there is still a lot of empty rhetoric in many donor nations’ development policies, which translates into little being done on the ground. He concedes that Nordic countries have led the way in terms of substantial efforts in this sector—particularly where the human rights approach is concerned. Although other countries have made positive steps forward, much of the efforts are couched within a traditional social-welfare mentality, seeing those with disabilities as deserving of charity and without the capacity to better their situations on their own. Mainstreaming disability into general development cooperation efforts has also proved problematic (Albert, 2004, pp. 8-14). At a conference in Helsinki in 2004 entitled, International Dialogue on Disability and Development, participants concluded:

…the disability and development landscape has been characterized by small, fragmented, unsustainable projects; a disconnect between disability and mainstream development efforts; a ‘flavor of the month’ approach to country focus; preoccupation with prevention, to the exclusion of rehabilitation and inclusion; ‘exclusion by design’ in mainstream projects; and poor coordination, evaluation and knowledge-sharing (Disability World, 2003 as cited in Albert, 2004, p. 13).

Although great advances have been made since 2004, it is astonishing that many national aid organizations still do not have official policies on disability and development. For instance, CIDA (Canadian International Development Association) has only recently done the research on which a future disability policy will be based (CIDA, 2008). Why is it that disability issues always seem to take a backseat to other priority areas in development efforts? The European Disability Forum’s Comprehensive Report on Development Cooperation (2003) posits that one reason may be the misunderstanding and ignorance surrounding what addressing disability entails. Many assume that making even a little progress involves great specialization and expense (i.e., in purchasing advanced adaptive technologies and making buildings accessible). However, the report
highlights that a starting point can be as simple as consulting individuals with disabilities to identify the barriers to inclusion so as not to erect them in the first place.

Finally, when disability issues are addressed, sensory and physical disabilities are often emphasized more than intellectual disabilities. Chappell (1998) has suggested that it is because of the perceived “curability” factor. This is particularly the case with physical impairments, where physical therapy or reconstructive surgeries can often cure or greatly alleviate the condition, or where ramps can easily be built to make buildings accessible. In other words, it is perceived that interventions with those who have minor physical and sensory disabilities may yield quicker, more tangible results (read: easier “success stories”), than working with those who have more severe physical or sensory disabilities, or those with intellectual disabilities. Perhaps for governments, it is easier (and thus more justifiable in terms of political maneuvering) to try and bring those with the least serious disabilities above the poverty line. Another factor may be that those with intellectual special needs often are not given a platform to voice their concerns, hopes and needs; it is assumed that many cannot advocate for themselves, or when they try, are not taken seriously. A third factor may be the “wallet-opening” visual impact of seeing people with physical and sensory disabilities. Since many NGO and aid organizations depend largely on citizens’ generosity, images of a child on crutches or a child struck blind may be more heart wrenching than seeing a child with an intellectual disability.

Overall, it is vital that development efforts do not leave those with disabilities behind, particularly since those with disabilities are often the poorest in society (poor in a monetary sense). In his keynote address at the World Bank’s first ever Disability and Inclusive Development Conference (2004), Amartya Sen noted that the poverty line for those with disabilities should take into consideration the fact that they incur extra expenses daily (i.e, in terms of aids, medication, transport requirements, etc.) and that they tend to have reduced ability to earn an income. In his address, and in a subsequent book, he referred to a PhD study done in the UK which determined that—in comparison to the general population in which 17.9% fell below the poverty line—23.1% of those with disabilities fell below the poverty line. When the costly adaptations to accommodate disability were also considered, 47.4% of those with significant disabilities fell below the poverty line (Sen, 2004). If these are the figures for a developed country, one can only
imagine what the poverty situation is like for individuals with disabilities, and their families, in many parts of the developing world.

In summary, if true development progress is to be made, it has to be progress for all, including the most economically and socially impoverished. True, holistic development seeks to help those least valued in a society, those seen as cast-offs (i.e., those with disabilities and their families). If their freedoms and capabilities to choose how to make the most of their lives are expanded, that is the test of true people-centered development (Sen, 1999, pp. 3-4)
Chapter 4: Analytical Framework

This chapter introduces the analytical framework that will be used to examine and interpret the findings.

As aforementioned, Friedmann’s social (dis) empowerment model will be the analytical framework used to try and shed light on the experiences of mothers raising children with significant disabilities in the developing world. In his model, he describes eight bases of social power and posits that without these things, one is socially disempowered (or poor) (Friedman, 1992, p. 66).

One of the important bases of social power is financial capacity; households must have enough monetary income, or credit, in order to buy the goods and services they require. Having strong formal or informal social networks is also important. These help a household to engage in reciprocal actions that benefit both parties (i.e., shared child care, information sharing, tool sharing, etc.). Families, friends, neighbors and colleagues tend to make-up the bulk of one’s social network. Another base of social power is surplus time (the amount of time available after the requirements of subsistence living have been met). The greater one’s surplus time is, the more time he/she has for leisure, pursuing sources of additional (non-essential) income, and for creating stronger social networks.

In terms of social organizations, Friedmann refers to this as both the formal and informal organizations that household members belong to (i.e., churches, sports clubs, parent groups, etc.). Membership typically accompanies an increase in social networks. As for “instruments of work and livelihood,” these refer to the tools of household production (i.e., tools for farming, healthy bodies and minds, and access to water). Having appropriate information is also vital. Friedmann notes that members of a household must have correct information about various aspects of their lives in order to make them better, and to move beyond subsistence living. For instance, knowing about openings in the labor market, the best child-rearing practices, the best tools for land cultivation and appropriate health-care information is all very important.

Knowledge and skills is another social base, and it refers to both the educational attainment of members in the household, and the mastery of the specific skills needed to make the household as prosperous as possible. Friedmann notes that each household
recognizes the need for at least some of its members to be as educated and skilled as possible. As for defensible life space, he describes it as: “The territorial base of the household economy…includes the physical space in which household members cook, eat, sleep, and secure their personal possessions” (ibid, p. 67). He also noted that this space extends beyond the immediate home to the wider community environment and is the most coveted social power of all, particularly if one can gain access to a friendly neighborhood in an urban environment (ibid, pp. 67-69).

This model is appropriate because a cursory exploration of the topic revealed that mothers of children with disabilities do tend to be impoverished in the developing world. This is the case, not only because of financial problems due to loss of income and the high cost of treatments, but because of negative societal attitudes and stigma that still surround disability in many low-income countries. This leads to social isolation for the mother and child. Indeed, in some African countries, families who have children with disabilities are forced to move to the outskirts of a town or village (losing their physical home as well as their status) (Chirwa, 2011). If the disability cannot be “fixed” (the medical model of disability), many societies are not yet willing to make the environmental or social adaptations to ensure the community is more accessible to those with disabilities (social model of disability). Furthermore, there is a lack of disability prevention, awareness and treatment information for parents in many developing countries, contributing to their feelings of helplessness (which further impoverish the household). These are just a few examples of why Friedmann’s disempowerment model is appropriate for this study, and it will help in assessing the extent to which these mothers are impoverished.
Chapter 5: Methodology

This chapter explores methodological issues pertinent to this paper, including how the articles for analysis were chosen (data base search, inclusion criteria) and why a literature review was deemed more valuable than a field study. The bulk of this section describes the 39 studies chosen for analysis. Limitations of the study are also discussed.

5.1 Reason for Choosing A Comparative-Analytical Literature Review

As aforementioned, I decided to do a comparative-analytical literature review of all the studies done in the developing world, because over three-dozen field studies have already been done, directly or indirectly, on mothers’ experiences in raising a child with disabilities. However, no researcher has—of yet—systematically compared those studies. Instead of adding one more field-study to the mix, I decided to do a comparative study.

5.2 Data Gathering Techniques

To gather data, I used various electronic search engines (such as EBSCO, JSTOR and PubMed) and searched many full-text databases concurrently through LibHub and Google Scholar to find appropriate scholarly articles. This was done through Linnaeus’ University’s library database in Växjö, Sweden. I did various searches using combinations of the following key words “disability, mothers, perceptions, intellectual disability, children, adolescents, developing world, impact, experiences, coping, poverty, social supports, culture, attitudes and beliefs.” Once no new results were appearing after many combinations of the above words in different search engines, I knew I had achieved information saturation. To make sure, I carefully looked through all of the literature reviews and reference lists of the articles I had chosen to see if other relevant studies were listed (that the electronic databases had missed). Several additional articles were found this way. To ensure that each article was of appropriate research quality, I went to each journal’s website to make sure the article came from a peer-reviewed journal.

5.3 Inclusion Criteria

After obtaining over fifty qualitative and quantitative articles, I set my inclusion criteria. Firstly, I wanted both qualitative and quantitative peer-reviewed articles, so that I would gain as much information as possible, especially since this field is still under researched. Secondly, mothers had to figure prominently in the article. Even if there

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12 Also, if I failed to examine all of the material available on this topic, recommendations for future research would be inadequate.
were other respondents (i.e., fathers, teachers, health practitioners), I still used the article if mothers’ perspectives were present and distinguishable from others.’ Thirdly, I was seeking studies carried out in the developing world, as many studies have already been done in developed countries on the impact on mothers’ of raising a child with disabilities. Therefore, I only chose studies from those countries that are listed as still developing by the UN’s Human Development Index—2010 (in other words, not one of the 42 countries having attained “very high human development”). Although numerous studies exist documenting immigrant mothers’/parents’ experiences in raising a child with disabilities in North America and Europe (often in ethnic communities similar to their home country), these studies were excluded due to the additional disability supports these western countries typically offer. As for the final two criteria, the mother had to be raising a child or adolescent with a disability, and that child had to be living in the household with the family (not in an institution). Living in the home was important to see how the disability impacted the mother (and wider family if applicable) on a day-to-day basis.

In summary, the chosen articles: 1) were either qualitative or quantitative in nature and peer reviewed, 2) had mothers as a respondent group, 3) focused on mothers raising children or adolescents with disabilities, 4) took place in the developing world, and 5) had a focus on children/adolescents living at home.13 Finally, it should be noted that, of the 50-plus articles found, more than 39 fit the inclusion criteria, but all of these additional studies were from Asia. Since almost 67% of the articles chosen were already from Asia, I decided against adding any more.

Some may question why articles examining mothers’ experiences raising adult children with disabilities were not included. Although this too is a worthy topic of exploration—and certainly belongs within this field of inquiry—it is beyond the scope of this study. Considering that 39 studies alone have been found that provide information on mothers’ situations in raising a child or adolescent with disabilities, to broaden the scope any further would likely mean a loss of analytical depth due to the sheer number of studies.

13 Note that most of the studies done in the developing world on this topic involve mothers raising children with intellectual disabilities. Therefore, children with physical or sensory disabilities will be, for the most part, underrepresented in this study.
5.4 Articles Chosen for Analysis

18 articles using qualitative (interview) research methods and 21 articles using quantitative (or a combination of quantitative/qualitative) research methods fit all five criteria, and so these were the ones chosen for analysis (39 in total). They will be grouped according to geographic region for ease of comparison.

Asia

South Asia:

Of the 39 studies done, twenty-six were conducted in Asia, of which ten were carried-out in South Asia. In India, five studies have been carried out. Peshwaria et al. (1998) interviewed 218 parents (120 families) from three different parts of the country about the facilitators and inhibitors that affected their coping in raising a child with an intellectual disability. The authors then analyzed the results statistically. In 2005, Majumdar et al. used qualitative and quantitative methods to measure stress and anxiety levels in 120 Indian parents of children with intellectual disabilities (60 having children with moderate to severe intellectual disabilities; the other 60, mild to moderate). The results were measured against a control group of 60 parents of children with normal IQ. Research done by Kalyanpur et al. (2007) looked at cultural and social barriers to twelve middle-upper class South Indian parents’ access to services and education for their disabled preschoolers and adolescents (aged 4-16). Semi-structured interviews and focus group discussions were the means of data collection. A study by Edwardraj et al. (2010), involved several focus group discussions with 62 Indian mothers, health workers and teachers that explored cultural beliefs and attitudes about intellectual disability. Finally, in a quantitative study on parenting stress in India, 102 parents were involved and did stress assessment tests: 30 did not have a child with an intellectual disability, and 72 did (Gupta and Kaur, 2010).

Of the two studies in Pakistan, Sabih and Sajid (2008) used stress indexes to examine stress levels in 60 parents (30 mothers and 30 fathers) raising children with autism aged 4-18. In 2010, Yousafzai et al. did a qualitative exploration on the impact of disabled children (aged 3-16) on the lives of their lower-income mothers in Karachi.
Finally, in Bangladesh, three studies have been done. In 2000, Mobarak et al. used qualitative and quantitative methods to determine predictors of stress in 91 poor mothers raising children with cerebral palsy (aged 1½ - 5). Also in 2000, McConachie et al. examined 47 mothers’ obstacles in accessing early intervention services for their children with cerebral palsy. 23 of the mothers were rural, and 24 lived in cities; their children were aged 2-5½. Finally, Maloni et al. (2010) examined the perceptions of eleven Bangladeshi mothers about disability, and their situation in general, through semi-structured interviews. Most of these mothers were from rural areas.14

**East Asia:**

As for East Asia, five interview-based (China, 4; Tibet, 1) and three statistical studies (all in China) have been carried out.15 An early study by Pearson and Chan (1993) in Guangzhou looked at the relationship between parenting stress and social support in 100 mothers raising children with learning disabilities.16 A study by Wong et al (2004) examined the perceived needs of 23 Chinese parents in raising a child with a developmental disability through focus group interviews and statistical analysis of the data. In 2007, McCabe did a qualitative study with 43 Chinese families (raising a child with autism) on the challenges of parental advocacy, particularly due to the social stigma surrounding disability in Chinese culture. The same researcher wrote a 2008 article (using the same data) about learning from parents’ perspectives in raising a child (aged 3-11) with autism and the importance of parent-to parent support. In a later study, she also examined the employment experiences, perspectives and wishes of 70 mothers of children with autism through semi-structured interviews (McCabe, 2010). In 2009, Wang and Michaels gathered qualitative and quantitative data about the perceived needs and available supports for 368 families raising a child with severe disabilities in Beijing and

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14 The majority of children had either spina bifida or cerebral palsy.  
15 Actually, a sixth qualitative study was carried-out in China, however it focused on mothers’ stress levels and social supports in raising their adult children with intellectual disabilities; therefore, it did not meet the inclusion criteria. Thirty Chinese mothers were interviewed, and the main stressors for them were behavioral issues and figuring out how to plan for the future (i.e., worrying about what would happen to their child once they died) (Chen and Tang, 1997). Also, approximately five studies have been carried out in Hong Kong that include mothers’ experiences in raising a child with disabilities, but as Hong Kong is now considered a highly developed country, studies from there did not meet the inclusion criteria.  
16 Their levels of stress were measured against a control group of 75 mothers raising children with no disabilities.
Shenyang (using survey packages). In 2010, Wang et al. used the same data (368 returned survey packages) to examine the overall stresses and coping strategies of these working class parents who were mostly raising children with autism and other developmental disabilities. As for Tibet, Scheidegger et al. (2010) looked at the daily lives and occupations of two families raising a child with disabilities in remote villages.

**South East Asia**

From South East Asia, two qualitative studies have been conducted (both from rural areas of Cambodia) and six quantitative studies (four from Malaysia and two from Vietnam). Note that all of the quantitative studies deal primarily with parental stress. As for the Malaysian studies, in 1998, Ong et al. did a study (using stress index questionnaires) on the stress levels of 87 mothers raising children with cerebral palsy, compared to a control group of 87 mothers raising healthy children (matched for age, sex and ethnicity). Multiple regression analysis was used to analyze the data. In 1999, Ong et al. did a similar study, but this time looked at the stress levels in 75 mothers raising a child with intellectual disabilities in general. Finally, in 2011, Ong et al. compared 66 mothers’ stress levels in raising children with spina bifida against a control group. Another study on parenting stress was carried out in 2010 by Norizan and Shamsuddin, but this time with Malaysian mothers raising children with Down syndrome. A cross-sectional study was done with 147 mothers using self-administered questionnaires.

Two similar studies out of Hue City, Vietnam, also focused on parenting stress. The first study by Shin et al. (2006) used standardized questionnaires to assess stress levels 106 mothers and 93 fathers raising children between the ages of 3 and 6 (all of whom were diagnosed with cognitive delay). In a similar study from 2009, only mothers were the focus; Shin and Nhan focused on predicting parenting stress in 225 mothers raising children with and without cognitive delay. Stress scales and other questionnaires were used to report both their levels of parenting stress and their social supports.

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17 34% of respondents were fathers (124), 59.2% mothers (216), and 6% grandparents, so mothers’ perspectives were the clear majority in this study.

18 The goal was to describe and report their experiences, perceptions and needs. This was done through participant observation and interviews.
Regarding the Cambodian studies, one examined 24 rural parents’ (15 mothers) views on family-centered rehabilitation for their child (aged 3-12) in rural Cambodia (Morgan and Tan, 2010). A year later, Morgan and Tan used the same sample of respondents to study their views on disability causation (i.e., cerebral palsy), and how these views impacted their behavior.  

**Middle East**

From the Middle-East, eight studies have been carried out (three statistical, four qualitative and one a mixture of both). Four studies were carried out in Turkey. In 2004, Eker and Tuzun evaluated the quality of life 40 Turkish mothers raising children with cerebral palsy (in comparison to 44 mothers raising children with only minor health problems). Data was collected via various surveys and then analyzed statistically. Another study by Diken (2006) examined how 13 Muslim mothers—mostly having low incomes and low education—interpreted the intellectual disability of their child (aged 4-18). The investigators focused on maternal perceptions surrounding the nature of disability, its causation and treatment. The study was qualitative in nature, and the information obtained through semi-structured interviews. Another qualitative study involved Bilgin and Kucuk (2010) examining 43 mothers’ perspectives in raising a child with autism (aged 6-17) through semi-structured interviews. The most recent Turkish study, a statistical one, used questionnaires and psychometric scales to assess stress levels, depression and anxiety in Turkish parents raising a disabled child, and to determine the relationship between these three variables Uskun and Gundogar (2010).

Elsewhere in the Middle East, Kermanshahi et al. (2008) did a phenomenological study (using semi-structured interviews) to examine six Iranian mothers’ perceptions of their lives with children who have intellectual disabilities. In that same year, Dehnavi et al. examined internalized stigma in Iranian mothers raising children with Down syndrome, and analyzed the data through a sample t-test and multiple regression. McConkey et al. (2008) studied the impact of 206 mothers bringing up children with intellectual

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19 Semi-structured interviews and small group discussions were the means to obtain data.
disabilities (aged 5-18) across three different cultures. Maternal perspectives from three different countries were obtained through qualitative and quantitative means (Jordan, Taiwan and Northern Ireland). For the purposes of my study, the Jordanian mothers’ voices were the focus (23% of the mothers). Finally, in 2010, Raman et al. looked at ten Kuwaiti mothers’ perceptions of their child’s disability using semi-structured interviews.

**Latin America**

As for Latin America, two studies have been carried out (one qualitative and one quantitative). In Guatemala, Saetermoe et al. (2004) did a qualitative study on lower-middle class caregivers (mostly mothers) of adolescents with severe physical disabilities in Guatemala City. The article chronicled the experiences of urban Ladino and Indigena parents as they tried to access Guatemala City’s array of urban health and educational services. More recently in Brazil, Terra et al. (2011) used surveys and statistical tools to assess the quality of life of thirty mothers raising children with cerebral palsy.

**Africa**

As for Africa, three studies met the inclusion criteria. Hartley et al. (2005) examined how caregivers of Ugandan children with disabilities cope, particularly mothers, and how they view CBR (Community Based Rehabilitation). 52 families participated, and they were recruited from three different areas of Uganda (one urban, two rural). The data was collected via participatory observation and semi-structured interviews, and of the 52 participants, 41 were mothers or grandmothers. In 2008, Abasiubong et al. examined the opinions and attitudes of 126 Nigerian mothers raising children with intellectual disabilities using the Attitude Scale. More recently, a study by Shabo et al. (2011) was carried out in Sudan, using qualitative and quantitative methods to gather data on the psychosocial impact on 146 parents of raising children with intellectual disabilities.

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20 The authors note that although they were officially “lower-middle class,” on average, they had more wealth and income than average Guatemalans, yet still struggled to meet their children’s educational and medical needs.

21 Note that there was a control group of eighteen mothers with healthy children.
Below is a summary pie chart on the articles used for analysis. The numbers in brackets are the number of studies that have been done in that particular region. Clearly there is an Asian bias to the data, and this will be discussed in the limitations section.

**Figure 1.1: Distribution of Thirty-Nine Studies in Developing World**

5.5 Coding

After gathering and reading the thirty-nine articles that dealt directly or indirectly with the impact on mothers of raising a child with moderate to severe disabilities, I began the coding process according to Friedmann’s eight bases of social power. I systematically went through each article, searching for quotes from mothers or discussions about mothers’ experiences in raising a child with disabilities that were pertinent to one or more of the bases of social power. I then placed every piece of relevant data under the corresponding research question that it helped to answer. In this way, I collected extensive material that reflected each of the bases of social power that Friedmann identified as key to empowerment or disempowerment (poverty). When one quote or discussion was relevant to one or more of the bases of social power, I included it under all relevant categories. Also, when I found recurring themes in mothers’ experiences that were not reflected in Friedmann’s model, I grouped these into categories of their own.

5.6 Dangers of Cross-Cultural Comparisons

Certainly there are dangers in cross-cultural comparisons, particularly when developing countries themselves differ so greatly in terms of culture, socio-economic stratification and social values and mores (Hatton, 2004). In cross-cultural studies, there can be
tendencies to simplify and generalize the data for comparisons’ sake. For instance, in comparing Asian and African cultures, one may be tempted to ignore the richness and diversity of subgroups within each culture (i.e., among Chinese people—see Yongling, 1991). To some extent, making generalizations is unavoidable. So long as the researcher is aware of this, care can be taken not to over-generalize or over-simplify. Perhaps because of these dangers, few researchers have attempted to search for commonalities among mothers’ experiences across cultures in raising a child with disabilities. I will have to be particularly careful about possible Asian generalizations in this research. As there are so many studies from different parts of Asia—and since Asia itself is so diverse—I have to guard against simplifications, and against coloring all of the developing world data with an Asian streak.

Another potential difficulty involves the use of standardized scales and measures across different cultures. Such scales may not be valid if they were created for, and tested within, one particularly culture (i.e., created with a North American orientation) (Berry et al., 2002). However, most—if not all—of the quantitative studies ensured that their scales were either developed in, or adapted to, the particular country (or region) of focus. Overall, as studies across cultures are clearly lacking, particularly with respect to mothers’ wellbeing and coping mechanisms in raising a child with significant disabilities, the gains for this study far outweigh any potential risks. (McConkey et al., 2008, p. 66).

5.7 Pre-understandings, Validity and Reliability

I myself have had extensive experience working in the disability sector (living and working with people who have intellectual special needs and their families). In addition, my own step-sister has profound special needs. Her biological mother is having difficulty coping in the Canadian context, not because of a lack of disability services or funding, but due to her own disability (early-onset Alzheimer’s disease). Hence, I have quite an interest in mothers’ experiences of raising children with disabilities. Far from being a limitation to this study, these experiences have helped me to better understand the situation of these mothers.

As for the validity and reliability of the study, using only peer-reviewed journal articles from a wide variety of sources, and ensuring that the articles chosen for analysis had used
scales and instruments appropriate for the country of study (see section 5.3), helped to increase the study’s validity and reliability.

5.8 Limitations of the Study

The data being heavily weighted towards Asia may at first seem problematic, but if generalizations are guarded against (see 5.3) there is no concern. Also, it is important to at least recognize that the majority of these studies have been carried-out in Asia, although the reason remains unknown. Certainly, it would have been better to analyze a more culturally representative sample across the developing world, but since the number of studies was limited—and since the majority of the developing world’s population is, in fact, Asian—it is not be too big of a drawback after all.

Secondly, I only worked with articles that had been written in English; there may be other legitimate studies offering a wealth of information, yet in other languages. Another limitation was that the focus of some studies was not on mothers’ perceptions about their situation in raising a child with a disability per say, but on others factors (i.e., their beliefs about the causes of disability, about effective treatments, etc.). Even so, in many studies, mothers did relate something about their experiences, their coping mechanisms, and about how cultural traditional views on disability impacted their lives. Also, the semi-structured interview approach in the majority of these studies allowed for women to share their wider experiences in relation to the article’s main focus. Another big drawback was that—as the majority of studies dealt with mothers raising children with intellectual disabilities—and because getting ethical clearance to work with children with moderate to profound intellectual disabilities can be quite daunting, I did not find any studies that sought out the voices of the children themselves.

Finally, although I chose articles from the developing world, it is clear that many socio-economic differences exist within the chosen countries, and that some areas of these countries have relatively high development and wealth.22 Although some articles

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22 For instance, a study from Goa (India) has been included, yet Goa province is one of the richest in India. Still, it is acceptable because India is still classified as a developing country, and even wealthy areas may have a “developing country” mentality in many respects. Still, it was hard to justify why a study from Goa, India should be included, and a study from Hong Kong should not (because Hong Kong is officially “developed”).
indicated the socioeconomic status of the participants (i.e., from rural areas, from lower-middle class communities, etc.,) other studies did not. Presumably then, some mothers may be living in higher wealth regions of their countries—and thus may have the resources and social connections to improve their situation. Even so, they would likely still have to face other things that impoverish (i.e., the stigma and alienation that surrounds disability).
Chapter 6: Findings and Analysis

This chapter reveals the most relevant data found in each of the 39 articles that pertains to one or more of the social bases of power that Friedman identified in his social (dis)empowerment model. Note that some of the categories overlap in terms of relevant data, and thus, much of the data could potentially be included under several categories. Please refer to the methodology section for a description of each study’s purpose, methodology and participants. This section also analyses the extent to which Friedman’s model is reflective of these mothers’ experiences.

6.1 Summary Chart of Findings

Appendix #1 is a summary chart of the findings, focusing on the top three bases of social power that were discussed in each of the 39 articles (labeled and colour-coded 1, 2 and 3). For instance, if an article spoke mostly about the financial concerns of raising a child with disabilities, a ‘1’ was placed under “Financial Issues” for that particular article. If the need for strong social networks was also discussed—but not as much as the financial component—it was labeled ‘2,’ and so on. If two bases of social power were referred to almost equally, they were both given the same numerical value (i.e., 1, 2 or 3). Therefore, at several places in the chart, there may be a few 1’s, 2’s or 3’s for any given article. Also, if there is only a ‘1’ and no other numbers for a given article, it means that the article in question only dealt with one base of social power (and did not discuss others). The benefit of this summary chart is to see which bases of social power the various authors felt were most lacking in these mothers’ lives.

The findings chart revealed that a majority of the 39 articles indicated that negative societal attitudes and beliefs about disability (new category), and the poor emotional and/or physical health of the mother in raising a child with disabilities (instruments of work and livelihood), were the biggest factors negatively impacting mothers’ lives. 17 of the 39 articles discussed instruments of work and livelihood the most (especially stress in the Malaysian articles), while 15 of the 39 articles emphasized first and foremost the detrimental effects of societal stigma and prejudice in raising a child with significant disabilities (particularly Asia and the Middle East). Note that it is quite difficult to separate Friedmann’s categories, as many of them overlap. For instance, deep societal

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23 This is not surprising, as Friedmann himself stated that the social bases are interdependent.

24 Although none of the authors referred explicitly to Friedmann’s model or “bases of social power” per say, it is clear that they understood the importance of social power in its various spheres due to the fact that most articles mentioned at least three of four of Friedmann’s bases.
stigma about disability can increase a mother’s stress level, thus decreasing her sense of well-being and increasing her sense of isolation. Thus, a mother’s emotional and mental health—an instrument of work and livelihood—is not only influenced by her direct caregiving experience, but by the multitude of other factors that shape her daily life, including societal stigma.

As for social networks, it too was discussed quite frequently. Indeed, 25 articles discussed the importance of mothers having a social life to such an extent that it was one of the top three bases of social power discussed. 3 of the 39 articles placed paramount emphasis on the importance of social networks (thus earning it a #1 place in the findings chart three times). Participation in formal or informal social organizations was not discussed much at all, but perhaps this was due to the fact that it is so similar to the social networks category.

About finances, 14 articles discussed it enough for the category to warrant a top three ranking in those articles. 3 articles discussed the negative financial situation of these mothers more than any other topic.

Regarding appropriate information and knowledge and skills, the former garnered 13 rankings in the top three on the chart, and 2 articles discussed it more than any other topic. 16 articles discussed the importance of mothers having the right knowledge and skills to help their child (enough to warrant a top three ranking), but none of the articles spoke about knowledge and skills as the primary topic.

As for having a lack of surplus time, 8 articles discussed it enough to warrant a top three ranking, although none of the articles gave it precedence. However, again noting the overlap between categories, a lack of surplus time to pursue other income generating activities could certainly contribute to mothers’ high stress levels (instruments of work and livelihood category).

In summary, although the importance of mothers maintaining sound physical and emotional health (instruments of work and livelihood), and the negative impact of societal stigma surrounding disability, were the most common themes of the articles, the
importance of mothers’ finding strong social networks was not far behind in importance. Indeed, interacting more with society and friends would not only improve mothers’ emotional and perhaps physical health (instruments), but would also facilitate the dismantling of negative stereotypes and prejudices surrounding disability. Again, this highlights the inter-relational nature of the categories. What follows is a more detailed elaboration of the findings for each of Friedmann’s bases of social power—plus a new category that Friedmann overlooked—followed by a brief analysis of each base.

6.2 Financial Resources
This category considers one’s ability to work and earn an income in order to contribute to the household economy, and specifically examines how mothers’ finances are impacted by raising a child with disabilities.

Asia
In India, Edwardraj et al. (2010) found that the financial cost was great in caring for a child with intellectual disabilities. A focus group of community health workers noted that, due to already limited resources, many mothers were unwilling to go to rehabilitation and invest in treatments unless there was a substantial gain (i.e., the child becoming independent). One community health worker said:

The mothers most often say, ‘It will be expensive to go to the hospital. Let him die if he has to. We have done enough. We might as well kill this child, rather than face financial problems’ (ibid, p. 742).

In addition to this pervasive sense of helplessness, the study also found that mothers from a lower socio-economic background expressed more negative feelings about their situations. In another study in India (Goa province), one of the secondary findings was that family income for households where no children with disabilities lived was 33.33% higher than those households that supported a member with intellectual disabilities (Majumdar et al., 2005).

As for coping mechanisms, Peshwaria et al. (1998) note that Indian mothers reported “financial support” as the third greatest facilitator in their coping (following informal social support and professional support). The investigators found that financial support was particularly important for those parents raising children with severe and profound
intellectual disabilities, because the cost of care for them is typically much greater. Less educated mothers cited “financial constraints” as a strong inhibitor to coping. Kalyanpur and Gowramma (2007) found that many parents were willing to re-locate for sake of their child with disabilities (i.e., move to cities where the best services are). Note that in this study, the mothers were of an upper caste, and could generally afford to put a great deal of money into their children’s welfare.25

Several Bangladeshi studies yielded significant insights in the financial realm. In a study by Mobarak et al. (2000), all of the mothers participating were poor.26 The findings were that this poverty—especially for women in rural areas who had less education than urban mothers—added significantly to levels of maternal stress. Indeed, these rural mothers had even greater difficulties accessing services, medicines and aids, due to their limited resources. Similarly, those women owning land plots less that half an acre reported greater maternal stress than those mothers with larger land plots.27 The investigators concluded that all of these mothers need economic empowerment (i.e., through micro-finance activities designed particularly for these mothers and their families).28

In another Bangladeshi study by McConachie et al. (2000) on what obstacles mothers face in bringing their children with cerebral palsy for early intervention services, many mothers indicated that the costs involved were prohibitive. The main problem cited was the cost of transportation. This study also highlighted the rural-urban divide, and found that rural mothers raising children with disabilities were younger, poorer and less educated on the whole in comparison to urban mothers. Finally, Maloni et al. (2010)

25 Mukherjee (2003) stated that it is not uncommon for middle and upper class Indian families to re-locate for the sake of their children with disabilities, even at great personal cost.  
26 For instance, they all had a GNP below the per capita value for Bangladesh— in 2000, the equivalent of $220 US/month.  
27 Interesting rural-urban comparisons were possible in this study, because the rehabilitation centers from which the participants were recruited (run by the Bangladesh Protibondhi “Disabled” Foundation) had both an urban base (in Dhaka) and a rural base (in Dhamrai). 49 mothers were recruited from the urban program, and 42 from the rural.  
28 Indeed, without such help, tragedy often results. A similar follow-up study of families struggling to cope with raising a child with special needs found that a significant number of the most severely disabled children—especially from the poorest rural families—had died from malnutrition between the end of the study and the follow-up period. (Khan et al., 1998, as cited in Mobarak et al., 2000, p. 431).
found that Bangladeshi mothers were willing to do almost anything for their children, including investing any amount of time and money to follow all of the therapies and hopefully find a cure. This was interesting, because most of these mothers were from rural areas, and therefore, most likely poorer than their urban counterparts.

As for East Asia, a study by McCabe (2010) examined the employment experiences, perspectives and wishes of Chinese mothers of children with autism. The findings revealed that some mothers gave-up employment once their child with autism was born, and that they saw this as a necessary—albeit difficult—sacrifice for the sake of the child (10 out of 32 mothers did this). However, note that in this study, parents had resources that many others in China did not, because they were able to afford help at the Autism Institute (either through their own funds or through borrowing). One mother reported having to pay double the tuition for her child with autism, because of the extra care and attention he/she would need in class. However, the fact that she had financial means can be seen in this excerpt:

But what can you do? Your own child, in order to get this kind of environment (with other children), to help him practice (his social skills), otherwise, if the teacher doesn’t accept you, he has no opportunity for instruction. So I figure, spending a little more is just spending a little more (ibid, p. 47).

In another Chinese study examining the stresses and coping strategies of working class parents raising children with autism and other development disabilities, Wang et al. (2010) found that among mothers, the unemployment rate was 30%, and for fathers, 40%. This was much higher than the national averages for the year that data was collected--2007 (4% unemployment rate in urban areas and 9% in most rural areas of China). The authors hypothesized that these high unemployment rates may have been due to the fact that some parents had given-up their jobs to move to the city where their disabled child could access educational and rehabilitative supports. They also noted that a large number of participants were from Shenyang, a poorer city compared to most. Regarding education, the authors noted that there are many private schools for children with autism, particularly in urban centers, but their tuition fees are out of reach for most families (Wang et al., 2010).
As for Tibet, Scheidegger et al. (2010) reported that the biggest challenge for parents was limited employment and lower household income, due to one parent always having to be home to care for the child. In a rural, poor area of Tibet, parents of children with disabilities were particularly hard pressed financially. As one parent always had to be home with the child, the household workforce was one instead of two (Scheidegger et al., 2010). The researchers noted that for one particularly poor family, both parents had to continue to work in the fields, “and the boy was behind a locked door, home alone” (ibid, p. 293). One mother reported that the other children suffer as well: “The other children in the house do not have milk to drink every day; they don’t get the best food” (ibid, p. 293).

Regarding studies in South East Asia, Ong et al. (1999), like Walker et al. (1989), found that in Malaysia, women not employed outside the home were particularly vulnerable to stress due to financial worries. In other words, maternal unemployment was a huge predictor of stress in mothers raising children with intellectual disabilities.29 In Cambodia, mothers were at risk of financial exploitation due to their vulnerability. As one mother stated:

Many traditional healers have come to my house, asking me to give them money, sometimes up to fifty thousand riel. Sometimes they have foretold this or that, and sometimes they have asked me to borrow money from others if I haven not had money to pay them…I don’t want to see my son having such a disability and I would give everything if my son could walk. But I don’t want to be cheated” (Morgan and Tan, 2011, p. 5).

**Middle East**

In Turkey, Uskun and Gundogar (2010) found that one of the most stressful factors for parents raising a child with disabilities was financial uncertainty. Another Turkish study found that 21% of mothers reported no support of any kind (including financial support) while 23% reported being helped financial by close family members. 33% of mothers

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29 In another Malaysian study, over half of the mothers had secondary school education (57.1%), yet only 28.6% worked outside the home. In addition, the data collection revealed that a majority of these families were living just above the poverty line by earning on average RM 700/month (US $184)—the poverty line was RM 660 in Peninsular Malaysia. (Norizan and Shamsuddin, 2010).
stated that they felt stronger through managing and maintaining their own budget, and not needing to rely on extended relatives.

**Latin America**

In Saetermoe *et al.*’s Guatemala study (2004), those families that struggled financially more than others were primarily concerned about their adolescent finding employment to contribute to the family income as quickly as possible (or at least to become self-reliant). For families that were slightly better off, the main concern was for the adolescent’s longer-term educational and professional wellbeing, and what would happen to him/her after the parents passed away. Note that many of the children in this study had serious physical disabilities, although some had intellectual disabilities as well. Many mothers lamented the high cost of medicine, and even though some were able to afford therapies and treatments, Guatemala’s third world status made it difficult to access the limited services. Others who could not afford the treatments emphasized how their child’s condition had deteriorated because of the lack of therapy or other interventions. Education is also expensive and hard to access in Guatemala, particularly for those with disabilities. One mother described how she told her daughter with disabilities that she would have to start working in order for the family to survive:

> This year I told her, ‘look my child…I cant send you [to NON-PROFIT]… I don’t have money for the bus, I am telling you the truth….’ So I told her, ‘look this year I need you to work, even if it means sweeping floors in an office or mopping.’ But it hurts me too because I don’t know how she will be treated by them (*ibid*, p. 1042).

**Africa**

In a Ugandan study, the authors noted that mothers spent much time and the little resources they had on seeking a cure, often moving between western therapists and traditional healers. However, as fathers served as the “gatekeepers” of the house, they ultimately decided where the limited funds would be spent. Therefore, even if mothers deemed it valuable to seek-out therapy or pay tuition fees, if their husbands did not agree, nothing could be done. As one mother stated, “My husband did not want me to take the child to Mulago; he thought the tablets we had given her at home would suffice” (*Hartley et al.*, 2005, p. 173). Often, there was no money for therapy, medicines, assistive devices and transport to the hospital, as it was a struggle just to get basic necessities for the whole
family. Even if the mother and child did manage to attend therapy, there were additional problems. As one mother reported, “I took her to Mbale, where they assessed her. She was given an appliance, but I do not have money for transport to fetch it” (ibid, p. 173). Even if the child could not walk, but could crawl, this too could get expensive: “She can move by crawling, but that in itself means that you have to have money to keep on buying soap and new clothes to maintain her hygiene…” (ibid, p. 173). Some mothers also reported that the father left the family once a child with disabilities was born, claiming that the child could not be his, thereby increasing the mother’s financial stress.

**Analysis:**
Overall, this study found that raising a child with significant disabilities greatly impacts a mother’s financial situation and ability to work outside the home. The exception was mothers from upper classes/castes where money was not a concern (i.e., some mothers in the Indian and Chinese studies, mostly from urban areas). For the most part though, a lack of social power in the financial realm really disempowered mothers, particularly those with lower socio-economic status in rural areas. Indeed, in many studies, mothers and their families lived at or below the poverty line, with lower household incomes than families raising non-disabled children. An Indian study showed that a household not raising a child with an intellectual disability has approximately 33.33% more income than a family that supports such a child (Majumdar et al., 2005). This suggests that: income is lost when one parent has to stay home to care for a child with disabilities, the costs of treatments, medicines and assistive aids are exorbitant, and families who have children with disabilities tend to be poorer in general (i.e., poverty being a cause and consequence of disability). However, more research needs to be done to ascertain the complex relationship between disability and poverty.

In addition, the studies showed that financial concerns and unemployment increased maternal stress, depression, feelings of despondency and despair. Many mothers reported giving-up their employment for the sake of their child (particularly in China), although these mothers at least had a choice in the matter. Other mothers from poor villages had to keep working simply to survive and left their disabled children at home (i.e., while they were working in the fields, in Tibet for instance). Interestingly, even those mothers with the resources to afford medical care, assistive devices and the costs of travel, were
disempowered due to the overall lack of disability services in their respective countries. Indeed, in many Asian countries, the social model of disability has not taken root; many governments fail to recognize that negative attitudes and environmental barriers have a role in contributing to disability.

As for the extended family, Indian mothers reported financial support from family as a key facilitator to their coping, particularly those mothers raising children with more severe disabilities. However, in many of the studies, mothers reported that extended family members were not forthcoming in terms of financial or social support (due to the stigma surrounding disability). Other mothers (i.e., in Uganda) were disempowered, because they did not have a say in how the household funds would be used in relation to the child’s disability, or whether they would be used at all.

One key difference in the studies was that, in some, mothers did not want to invest in treatments unless they would see a substantial improvement in their child (i.e., walking or independence) (Edwardraj et al., 2010). In other studies however, mothers were willing to try almost any treatment, or bear any expense, for an improvement in the child. One would assume that this latter group would constitute only well-off mothers (as indeed it did in Kalyanpur and Gowramma’s 2007 Indian study). However, the same was true for poor Bangladeshi mothers in Maloni et al.’s 2010 study, who would often borrow from friends and relatives to seek out new treatments. Therefore, more research needs to be done on what motivates and deters mothers from seeking therapy for their children, and why some are more willing to invest than others, given similar poverty levels. Unfortunately, as some articles did not relay the socio-economic status of their participants—or just gave their education level—it was hard to determine how much finances dictated their decisions.

Finally, it was interesting that, although finances was a major concern for most mothers, in the vast majority of articles, it was not among the top three most discussed issues. This may suggest that the overall stress of caring for a child with disabilities (a stress that is often compounded by financial concerns), and the social isolation that results from having a child with a disability, impacts mothers more than financial stress alone every could.
6.3 Social Networks

This category discusses the extent of mothers’ meaningful relationships with family, friends, the neighborhood and the larger community.

Asia

In Edwardraj et al.’s 2010 study, Indian mothers claimed that they had very little support and help from family, friends and society in general in caring for their child with intellectual special needs. Another mother spoke about society’s aversion to her and her child: “People mock us. They shut their doors when we go there” (ibid, p. 743). A health worker concurred by saying that society does not generally help these families, and in villages, people avoid going near their homes. All participants agreed that the myths and stigma surrounding disability in India (particularly the common belief that the mothers are to blame), contribute to their social isolation. Health workers noted that extended family members typically do not accept the disability and do not offer support, except for cases where the mother’s family may step-in to help.

In another Indian study by Peshwaria et al. (1998), mothers reported a bit more family help. They stated that informal social support from inside and outside the family was the biggest facilitator in their coping, followed by professional support. Mothers, much more than fathers, stated that social support from the family was essential for coping. However, the article also mentioned that some of the mothers found their extended relatives to be quite unhelpful, particularly on the husband’s side.

Similarly, Kalyanpur and Gowramma (2007) found that extended families could be a source of social support or anxiety, depending on the family and circumstances. Some mothers were quite close to their in-laws and relied on them for childcare and for financial help. Although quite helpful at times, mothers also reported that the extended family was often too opinionated about what should be done for the child, and held much sway in decision-making. Some in-laws were reported to be cruel. Since they themselves were embarrassed about their grandchild’s disability (holding to traditional beliefs about

30 The investigators explained that since mothers are under great pressure to balance childcare with household chores, to have extra help from family members was seen as a great relief, particularly when the child had behavioral problems.
disability more than younger generations), they restricted both the mother and child’s social interactions. For instance, one mother reported:

When guests came to our house, my in-laws warned me not to come outside with my child. They scolded me and accused me for everything he does. They compare him with other children and they say, ‘He is mad.’ Sometimes when I heard such complaints from my in-laws, I thought about committing suicide (ibid, p. 75).

Many mothers stated that they were aware of how their children brought embarrassment and shame to the family, particularly if the child had strange or aggressive behavior patterns. Kalyanpur and Gowramma (2007) noted that the mother received more social support from the family when the family believed that the child would eventually become “normal” with some help. But the more different the child looked, or the more abnormal he/she behaved, the more likely the family’s rejection would be. The authors cited another study showing that mothers were reluctant to go out socially, or to invite people over to their homes, out of fear of embarrassment (Sen and Tuli, 1991, as cited in Kalyanpur and Gowramma, 2007, p. 75).

In Pakistan also, mothers found that the stigma still surrounding disability hindered their social lives and enjoyment of life (Yousafzai et al., 2010). As for Bangladesh, Maloni et al. (2010) found that although mothers have adopted a biomedical understanding of disability and treatment, family elders create conflict by insisting that traditional healing approaches be used. The mothers reported that this further alienates and isolates them from the rest of the family, and suggested that education is needed to teach elders about the biomedical causes of disability. These mothers also emphasized how helpful it was to talk informally with other mothers at the rehabilitation centre (and how they felt that they finally belonged somewhere), and suggested that formal parent-to-parent programs start for socialization and knowledge sharing.31 As for husbands, one mother reported that her husband had threatened to leave her and marry someone else if she did not come back from therapy with a ‘normal’ child (ibid, p. 6).

31 Indeed, the researchers cited another study wherein parents with positive perceptions of their children with disabilities were able to encourage other parents to think more positively and think realistically about their child’s situation (Gupta and Singhal, 2004, as cited in Maloni et al., 2010, p. 8).
In East Asia, Wang and Michaels (2009) found that both Chinese mothers and fathers stated that their current level of social support from family, friends and colleagues was inadequate. They relied most heavily on the child’s school, on each other (the parents) and on extended family, but all of this was deemed insufficient to cope with life’s daily challenges. In this study, mothers generally perceived a greater need for social supports than fathers, and parents raising autistic children had much higher perceived needs than other parents.

In McCabe’s 2008 study, it was found that mothers of children with autism particularly emphasized the need for more parent-to-parent support. They stated that only other mothers raising children with autism could understand what they were going through, and meeting together was a strong source of social contact and support. McCabe noted that many families indicated that they knew of other families in their area with children with autism, but those families never admitted that they had a child with autism due to the stigma involved, and thus never sought help.

A 2002 study carried out by Pearson and Chan (in Guangzhou), revealed that most of the 100 mothers sampled had significantly greater stress and less social support than mothers of non-disabled children. Finally, in Tibet, parents noted that they had become socially isolated since having a child with disabilities. As one mother said: “Sometimes relatives don’t like to come to Tserang’s house [the child with disabilities], because of his ‘situation,’” and another, “Neighbors look down on her sometimes, because she is not normal, even relatives do so. We only take her to very close ones” (Scheidegger et al., 2010, p. 294).

In South East Asia, Ong et al. (1999), found that Malaysian women not employed outside the home (due to increased care giving demands) were particularly susceptible to stress and depression, due in part to the loss of social contacts that one makes outside the home. Therefore, it seems that the ability to work outside the home is key to reducing social isolation. In Norizan and Shamsuddin’s (2010) study, the importance of strong

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32 In comparison to these housewives, more than half of the women in this particular study were in fact working outside the home—and thus were not the main caregivers. These women did not report more feelings of ill-health or social isolation in comparison to the control group.
social networks for coping was also emphasized among the sample size of 147 Malaysian mothers raising children with Down syndrome. The authors stated, “In the acceptance process, mothers have to seek help...Through communication with others and exposure to others in similar situations, mothers may realize that their children’s condition was not the worst” (ibid, p. 1001; similar findings to Lam and MacKenzie’s 2002 study). As for other countries in South East Asia, mothers in Vietnam (raising children with cognitive delays) also reported that they had fewer social supports than they needed (Shin and Nhan, 2009).

**Middle East**

In Uskun and Gundogar’s Turkish study (2010), it was found that negative societal attitudes towards the disabled, and the complexity of caregiving required, led to fewer social interactions for parents and their children. This social frustration was one of the top three stress determinants (along with finances and loss of free time).

Also in Turkey, Bilgin and Kucuk’s (2010) found that 44% of Turkish mothers reported that they struggled with insufficient support from the family, particularly their husbands, and thus had difficulties fulfilling their various familial roles. As one mother stated: “Everyone left me alone, including my husband. I was exhausted either physically or mentally” (ibid, p. 94). Interestingly, in this same study, 35% of mothers said that the role of caregiver was shared equally between the mother and father. One mother even stated that the disability caused her and her husband to grow closer. Regarding social ties outside the family, many mothers reported great benefits in talking with other mothers in similar situations to theirs: “At first, I could not accept this condition. But, after I met other mothers having similar problems as we do…I began to accept our situation more easily. It is a kind of therapy, together with the other mothers here” (ibid, p. 94). Indeed, Bilgin and Kucuk found that mothers lacking social activity are more vulnerable to the psychological stresses that accompany complex care for a child with disabilities.33

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33 As Turkey is a culture that highly values solidarity, mutual support and sharing among family and friends—and since it is believed that problems can be resolved through talking with others—the authors reported that mothers without these social supports are particularly at risk.
In Iran, Kermanshahi et al. (2008) reported inadequate support to Iranian mothers from the family and community. One mother said, “I am very sensitive to others’ behavior and comments aimed at my child… Therefore, I always stay at home because people don’t understand our child, and we hardly have any relationships…” (ibid, p. 322). Mothers in this study noted that when husbands did help, it was a big support (although most said it did not happen very often). Also, mothers emphasized the pain that family rejection brought, as evidenced by this mother’s statement:

It took a lot of trouble for my son to speak a word, so hard; for ten years; this is a lifetime (saying with stress)…when he says ‘hello’ to his grandfather, he doesn’t pay any attention to him. This behavior is very painful for me, as though a person had put a sword in my heart (ibid, p. 323).

Kermanshahi et al. noted that some grandparents blamed parents, especially mothers, for the child’s disability, and so did not accept the grandchild.

Elsewhere in the Middle East, mothers related feelings that friends, family and colleagues did not understand their situation, particularly the enormity of their care giving role and the exhaustion and stress they felt (Raman et al., 2010). In Jordan, more negative social interactions within the family were reported by mothers who rented or shared accommodation, had less education, and had children with greater behavioral problems. One Jordanian mother said, “Nobody helps us except for my brother…he brings my child things for the computer” (McKonkey et al., 2005, p. 71).

**Africa**

Interestingly, the study from Sudan (Shabo et al., 2011) reported that out of 146 parents participating, 65% reported no changes to their social lives since having a child with intellectual disabilities. Of the 35% of families who reported that their social lives did suffer, mothers reported a significantly greater impact than fathers. As for the Ugandan study, many mothers reported that their social lives suffered tremendously, due to constantly being in the home to care for their disabled child (Hartley et al., 2005).

**Analysis**

Although not a lot was mentioned in the studies about social organizations (other than the fact that mothers wanted more parent-to-parent formal support groups), much was written
about social networks. The two are actually quite similar, as participation in social organizations (i.e., churches, credit circles) tends to increase one’s social networks. In most of the developing world studies, where social support was mentioned, mothers reported having inadequate social networks yet claimed that socializing was critical for their coping. Most said that socializing with mothers’ in a similar situation would be most helpful.

Although a few studies reported some familial support (particularly from the mother’s female relatives), the vast majority of studies found that the extended family (particularly in-laws) were not much support and often blamed the mother for the child’s disability. The social ties in the family also began to disintegrate when elders insisted on traditional methods of treatment while most mothers wanted to follow a biomedical approach to therapy. The result was that the elders’ advice was usually followed, albeit reluctantly.

Across the developing world, numerous mothers reported feelings of social isolation, and they explained that the stigma and myths about disability in society (including the notion that mothers must have sinned to have a disabled child) contributed greatly to their isolation. In other words, social networks and societal beliefs are two bases of social power that are closely tied. A case in point was epilepsy in the Ugandan study; it was noted that some mothers refuse to let their children play with children with epilepsy, or visit their home, due to misinformed fears of contagion (Hartley et al., 2005). This leaves both the mother and child isolated.

Finally, from looking at the studies as a whole, it seems that mothers have the least social contacts when they: are stay-at-home mothers, have a child with more severe disabilities (who requires more time-consuming care), have a child with more behavior problems (which makes it hard to go out in public), are poor and less educated. The one study that stood out from the rest was the Ugandan study, in which 65% of mothers said that there was no impact to their social lives after having a child with disabilities. Since this seems to contradict the other studies, it warrants more investigation.
6.4 Surplus Time Above Subsistence Requirements

This category examines mothers’ abilities to have additional time above subsistence requirements to pursue educational, investment, health opportunities, etc. while raising a child with disabilities.

Asia

In Edwardraj et al.’s focus group study in India (2010), the authors found that mothers were expected to fulfill all of their typical roles, in addition to caring full-time for their disabled child. As one mother noted:

> It is impossible to look after a disabled child in a joint family. The other family members expect us to take care of their needs rather than the child’s...Mothers are forced to take on the entire responsibility of caring for the child...Fathers do not participate... (ibid, p. 742).

The health workers and teachers in the study concurred that the main care-giving responsibilities are the mothers,’ with little understanding or assistance from others. Therefore, the mother has to share her time between housework and caring for other children. The mothers continually cited their despair over their child’s lack of independence, and that so much of their free time was spent assisting with mobility and daily care tasks (Edwardraj et al., 2010).

In Bangladesh, McConachie et al. (2000) found that although many mothers would have liked to take their children with cerebral palsy to therapy, not only was the cost prohibitive, but so too the traditional expectation that mothers should be engaged in housework and caring for the other children. This common societal attitude (especially among husbands and in-laws) left mothers with no time to seek out rehabilitation services for their disabled children. For mothers that did take their children for therapy, the distance of travel, not to mention the poor state of the roads (making the journey even longer) were cited as obstacles to attendance. Not only does the cost of such travel have to be considered but the time that it takes.

In another Bangladesh study by Mobarak et al. (2000), women raising children with cerebral palsy reported that the child’s lack of independence was the biggest stressor
(75.46%), followed by the child not sleeping well (waking up many times in the night needing assistance) bed wetting, soiling and being hyperactive. All of this means that mothers have much less time to pursue other necessary tasks that benefit the household (ibid, p. 431). The older the child became, the greater the reported maternal stress levels. The authors suggest that this is because mothers expect to expend much energy on helping small children, but when children age and still require as much help as when they were infants, the reality sets in that this child will likely need life-long care. Therefore, the mother realizes that she will never really have free time as she ages. The authors recommended that more informal sources of support be introduced to free-up mothers’ time.

As for Pakistan, mothers also feel a lack of caregiving support and stated that they do most of the work themselves. As one mother said: “For those of us with special children, we never have the opportunity to rest in the afternoon,” and “Mothers of normal children do not have so much work to do, when a child is one year old he starts to eat some things independently” (Yousafzai et al., 2010, p. 6).

In East Asia, Wang et al. (2010) found that, in order to cope with the demands of daily life, Chinese mothers suppressed competing activities more often than fathers (Wang et al., 2010). Also, the investigators’ findings confirmed previous studies that mothers were expected to take on three roles at the same time: caregiver, wage earner and teacher of the child. (Huang et al. 1998; McCabe, 2008). This was speculated to be one of the reasons why mothers perceived greater overall stress than fathers in China. Wang et al. (2010) used statistics from 2009, which revealed that 36% of all children with disabilities in China were not receiving a formal education (Beijing University and National Bureau of Statistics of China, 2009). Indeed many schools in China still reject children with special needs, particularly autism (MCabe, 2007). This means that mothers become the main teachers, and are home with their children even more, having even less free time.

**Middle East**

In Raman et al.’s Kuwait study (2010), the authors included numerous excerpts of mothers’ feelings of exhaustion and stress in relation to their enormous care-giving role and how this has influenced their lives (i.e., lack of balance between professional careers
and family life, and feeling that there is never enough time in a day). Indeed, the mothers reported often feeling overwhelmed with the immense time that daily caregiving tasks and medical appointments consumed, leaving little time for housework and caring for other children. Since mothers were not meeting the traditional expectations to carry out many roles at once well in the family unit, they reported disharmony in the family at times. This is how one mother described her lack of free time: “Once I finish my work, I go home directly and always stay with her, and I don’t leave her unless there is something important…I’m always with her” (ibid, p. 53). Another mother complained that a therapist asked her to do two hours of therapy a day with her child at home, in addition to all of her other tasks and responsibilities.

Iranian mothers also found that all of their time and energy was consumed with caregiving tasks and medical appointments, “devoting self to the child” (in addition to housework and caring for other children) (Kermanshahi et al., 2008, p. 321). The authors found that “…these mothers allocated less time for themselves, rested and entertained less than other mothers” (ibid).

**Africa**

Hartley et al. (2005) found that mothers (or other female caregivers) are in much need of time away from their disabled child, and so formal or informal respite care was strongly recommended by the authors. They too emphasized that the majority of caregiving activities falls to the mother, or, in the case of her illness or death, the grandmother. One mother said that she “shoulders the responsibility alone” (ibid, p. 173). Fathers were mostly absent in day-to-day care, and mothers received little rest. As one child said, “She feeds her, bathes her, and every other thing you can think of. It is only mummy who does all this. We wonder what would happen if mummy passed away” (ibid). However, the investigators did note that, at times, female relatives and community friends would come and offer help, so that mothers could rest or take care of other household tasks (like gathering firewood). One mother reported that the child’s siblings would help by pushing their brother around town in a wheelchair and to church.
Analysis

In all of the studies that discussed time, mothers across the developing world emphasized their disempowerment in that they had little to no surplus time to pursue other life-enhancing activities (i.e., additional income generation activities, educational pursuits, etc.). All of their waking hours were spent: caring for their child with disabilities, taking him/her to appointments, doing home therapy, caring for other children, doing household chores and caring for in-laws. In China, mothers were also their children’s teachers, as many schools refused to admit children with autism. As for the mothers who worked outside the home, once they got home, they devoted themselves to caring for their child until bedtime. Even during the night, many mothers had to wake-up to help their child with toileting, etc. As a result, many mothers reported feelings of exhaustion.

6.5 Social Organizations

This category involves one’s ability to participate in organizations and functions outside the home. Quite often, participation in social organizations increases one’s social networks (Friedmann, 1992, p. 68).

Asia

Edwardraj et al. (2010) found that Indian mothers were almost totally deprived of a social life (including any involvement with clubs or activities of interest outside the home), due to their heavy caregiving and housework demands. Also, in India, Kalyanpur and Gowramma (2007) found that Indian mothers were not involved in much organizational life. For instance, only one mother was involved in a parent organization, and she appeared to get most of her information from this group of parents, not to mention social support. The investigators noted that in Indian society, some still believe that mothers are not supposed to be advocates for their children (something that parent organizations typically promote, encouraging parents to search for more information and better treatment options). As it is still a patriarchal country in many respects, some believe that women are supposed to listen to professionals, do as they are told and not ask questions.

In numerous studies, many mothers emphasized the importance and necessity of starting parent-to-parent formal organizations for a reliable source of social support and information exchange (i.e., McCabe, 2008). Aside from this, not much information about
participation in social organizations was found in the data, as most mothers just spoke about their friend and family support networks. Therefore, see “social networks” above for an analysis of the data.

6.6 Instruments of Work and Livelihood

In the context of this paper, “instruments of work and livelihood” refers to a mother’s ability to maintain her own health (physical, emotional, spiritual, etc.), particularly since her body and mind (tools of work) are so involved in caring for the child with disabilities.

Asia

In Edwardraj et al.’s (2010) study, health workers noted that Indian mothers were often depressed, blamed themselves for their child’s condition, felt guilty for wishing their child had not been born, and wished that either they or their child would die. Majumdar et al. (2005) found that the more severely disabled the child was, the higher the Indian mothers rated their level of mental stress (in comparison to mothers with children with lesser disabilities). Another quantitative study in India also showed that both physical and mental stress is high among mothers raising children with intellectual disabilities, and that for mothers and fathers, mental stress usually surpasses any physical stress (Gupta and Kaur, 2010). Although high for both parents, mothers scored significantly higher in terms of mental stress than fathers. The authors suggest that coming to grips of what it will mean to care for a child with intellectual disabilities, day in and day out for years, takes its toll on parents mentally more than physically, particularly mothers as they do most of the daily caregiving tasks (ibid, p. 123). Peshwaria et al. (1998) found that having social, financial and professional support was seen as aiding the coping process (more than having faith in God), whereas behavior problems in the child, a lack of acceptance by society and financial problems were some of the things that hindered coping (and increased stress). In addition, Kalyanpur and Gowramma (2007) noted that many Indian mothers were highly stressed about the possibility of their children being taken advantage of.

As for Pakistan, Sabih and Sajid’s (2008) research examining stress among Pakistani parents raising a child with autism found that mothers: tend to be significantly more stressed than fathers and have poorer mental health, find raising a girl with autism more
stressful than a boy, and feel increasingly stressed as the child ages (and less able to cope). The authors noted that in Pakistan, mothers carry the burden of child-care and housework responsibilities, so this may be the reason accounting for the higher maternal stress. Also, since studies have shown that Pakistani parents typically worry about girl children more than boys (and about their future), raising a girl with autism compounds this stress and anxiety, particularly when she reaches adolescence and the mother has to cope with her menstruation and increased fears of sexual assault. Yousafzai et al. (2010) also emphasized this particular stress among Pakistani mothers. As for there being a positive correlation between older children and stress, the authors noted that it is likely that as children age, parents begin to fully realize the life-long implications of the child’s disability.

In Mobarak et al.’s (2000) study on predictors of maternal stress in Bangladeshi mothers, the authors found that 41.8% of mothers were at risk for psychiatric morbidity (illness). In addition to the child’s lack of independence (the biggest stressor), other stressors that may contribute to mental illness are: living in a rural area and being in a poor family. The study found that as stress increased, mothers’ ability to cope with their child’s needs and demands lessened.

Regarding East Asia, Chinese mothers particularly seem to suffer from high levels of maternal stress, perhaps due to cultural expectations for child performance in China (see Wang et al., 2010). The five most reported means of coping were: acceptance, active coping, positive reinterpretation (of disability) and growth, suppression of competing activities and planning. Mothers reported more stress in raising children with autism than those mothers raising children with other forms of intellectual disability.

As for South East Asia, Shin et al. (2006) examined parental stress in raising children with and without cognitive delay in Vietnam. In general, mothers experienced more stress than fathers, and this was explained in part because of the greater caregiving burden that mothers have. Mothers having children with lower IQ’s than other children, having a female child with disabilities, and having a husband with health issues, all greatly elevated maternal stress. Also, the greater the perceived stigma by society and family towards the child, the greater the stress levels for both parents.
Malaysian studies showed that mothers raising children with cerebral palsy (Ong et al., 2008), spina bifida (Ong et al., 2011), and Down syndrome (Norizan and Shamsuddin, 2010) have greater stress than control groups and groups of mothers raising children with lesser disabilities. Regarding the Norizan and Shamsuddin study, the authors noted that typically, mothers raising children with Down syndrome report less stress than mothers raising children with other intellectual disabilities (i.e., autism), and suggest that this is because children with Down syndrome typically have an agreeable and cheerful demeanor. Other findings in this study were that children’s behavior problems (i.e., a lack of independence, tantrums), maternal depression and a lack of acceptance of the child’s condition were strong contributing factors to maternal stress. The authors also found that positive coping strategies (particularly religious ones) helped to reduce maternal stress. Also, in this study, single mothers reported more parenting stress than married ones.

As for Malay mothers raising children with cerebral palsy, several things were positively correlated with maternal stress: the number of hospital admissions for the child, being of a certain ethnic background (i.e., Chinese Malays) and having little education (Ong et al., 2008). In the spina bifida study, mothers were less educated, had lower household income, were more likely to be unemployed, and more likely to be the main caregiver (Ong et al., 2011). The authors note that the “potential loss of self-esteem when a woman’s self identity is subsumed by her role as mother and wife may be contributory factors” (to the stress and depression) (Ong et al., 1999, p. 361). Also in this spina bifida study, the researchers found that mothers’ perceptions of their children’s disability influenced their stress levels more than the actual severity of the child’s condition. Hence, the authors recommended interventions for mothers’ to help transform their negative perceptions, and thus improve their mental health (Ong et al., 2011, p. 58).

**Middle East**

In Iran, Kermanshahi et al. (2008) showed the emotional and psychological pain that many mothers experience. One said, “my son is 9 years old now, but I feel I have endured 90 years of physical and psychological pressures…” (ibid, p. 321). Another mother shared:

Sometimes I come across mothers who are very old but still have to take along
with them a grown-up adult. Immediately, it reminds me of my own situation and tears come to my eyes. It seems that I am seeing my own future in them… (ibid, p. 323).

In Jordan, mothers raising a child with intellectual disabilities had poor mental health, due in part to high child-related stress (particularly behavior problems). The authors noted that the mothers’ stress was not lessened through professional support or through adopting coping strategies, and single mothers had poorer mental health than married mothers (McConkey et al., 2008).

A pilot study out of Turkey in 2004 (Eker and Tuzun) investigated whether mothers raising children with cerebral palsy rated their quality of life lower than mothers raising children with minor disabilities. Overwhelmingly, mothers did rate their quality of life much lower than the comparison group. They rated their physical health as particularly low. The authors surmised that inadequate sleep and rest, and not having time to see a doctor for their own health issues, may be the cause of this low rating. They also posited that manual handling may play a significant role in mothers’ poor physical health, because many mothers do a lot of lifting, carrying, dressing and bathing of their children with cerebral palsy. Among the mothers raising a child with cerebral palsy, those whose children had more severe mobility issues (needing extra with daily tasks) rated their quality of life even lower than mothers with higher-functioning children.

In Bilgin and Kucuk’s (2010) study, the researchers found that Turkish mothers raising children with autism reported: grief (18.6%), emotional breakdown (11.6%), worry (9%) and hopelessness (9%). In addition, most mothers reported periods of short or long depression. Kuwaiti mothers also reported a great deal of distress over their constant fatigue and stress in relation to their heavy caregiving role (Raman et al., 2010).

**Latin America**

In Brazil, in 2011, Terra et al. examined 30 mothers of children raising a child with cerebral palsy against a control group of 18 mothers raising healthy children, and found that the former group scored much lower for perceived quality of life. The authors also found that mothers of children with cerebral palsy and epilepsy combined scored lower
than mothers of children with cerebral palsy alone. A big factor in their low quality of life scores was their high stress levels.

Africa
In a study from Sudan, in which 82 mothers were interviewed about their lives raising children with intellectual disabilities, 70% of parents reported moderate to severe anxiety about their situations, while 51.2% of mothers reported moderate depression and 30% reported symptoms of severe depression (Shabo et al., 2011). Ugandan mothers also reported stress due to the constant demands, lack of a social life and little free time; the stress tended to manifest itself in physical ailments. As one sibling stated, “Mummy has developed chest pains and backaches as a result of lifting her” (Hartley et al., 2005, p. 173). The researchers noted that most of the mothers appeared lethargic and full of fatigue during participatory observation, and that most of their reported stress involved worrying about their children’s future (Hartley et al., 2005).

Analysis
A review of the 39 articles revealed that all mothers raising children with significant disabilities in the developing world are mentally and physically tired, and most are exhausted. The studies particularly mentioned mothers’ high stress levels (more than fathers), and emphasized that mental stress far surpassed any physical strain the mothers experienced. In addition, there was a positive correlation between the severity of the disability and stress levels. Many mothers reported feelings of depression, and some, thoughts of suicide or infanticide. From a survey of the articles, it seems that the most common predictors of poor mental health were: having a child with more severe disabilities, having poor social networks, being poor and from a rural area, having a child with behavior problems, being a single mom, having a girl with disabilities (or an older child), and experiencing disability-related stigma. As for physical wellbeing, the less independent the child was, the more physical stress the mother reported (due to having to manoeuvre the child). Finally, out of all the cultures, it appeared that Chinese mothers have particularly high stress levels, perhaps because of the high expectations of children in Chinese society.
Indeed, if mothers are not at the top of their form mentally and emotionally, they cannot go about their daily tasks well. In Friedmann’s model of social (dis) empowerment, he did not emphasize the mind as an important instrument that must be safeguarded for a family’s livelihood and wellbeing.

6.7 Appropriate Information

This category involves the impact on a mother’s ability to make informed decisions for her child with disabilities to make both of their lives better. True knowledge on an issue is predicated on having appropriate information about it. Note the overlap, therefore, between this category and the next, ‘knowledge and skills.’

Asia

In India, Edwardraj et al. (2010) found that many mothers did not have appropriate information about their child’s condition, how to best help him/her, and how to access health care resources (ibid, p. 742). One of the ramifications of not having enough information, or inaccurate information, is that mothers can have unrealistic hopes. As one mother said about a child with significant intellectual disabilities: “It is possible to make him normal, when training is provided” (ibid, p. 740). Edwardraj et al. (2010) also noted that when others in society do not have enough information about disability, this too is problematic for the mother and child. For instance, when someone does not have accurate information about the possible improvements that therapy can bring, blanket statements can be made such as the one by this health worker: “There is no benefit in spending money on a disabled child. He will never become alright” (ibid, p. 741). In this way, negative societal attitudes are perpetuated, and mothers forgo treatment because a cure is not possible (even though therapy would likely improve the child’s condition somewhat).

Interestingly, Edwardraj et al. noted that many educated mothers did have appropriate information but still did not seek out therapy due to the stigma and shame surrounding disability, and out of fear that others would find about their child’s condition. Therefore, having appropriate information is not enough in and of itself; a mother has to have the desire and incentive to act on it. Unfortunately, the negative attitudes that prevail in Indian society may cause a mother to avoid seeking help. In the Indian study by Peshwaria et al. (1998), many mothers did ask for help, particularly in the areas of: their
children’s behavioral problems, training in activities of daily living and timely advice on diagnosis.

Also in India, Kalyanpur and Gowramma (2007) found that parents, even those with wealth and resources, still had trouble accessing information about their child’s disability and available services in India. This was due to: the lack of proper infrastructure to disseminate information, the negative attitudes and perceptions about disability that still abound in India, and the hierarchical and paternalistic relationship between parents and professionals (where asking questions is still taboo). One mother said: “Parents were never allowed inside to observe the therapy. Once the child is taken inside, what they do is unknown to us. (Even) when I asked, I was not told” (ibid, p. 76). Also, the investigators noted that in this study, no mothers worked outside the home (despite being highly educated), perhaps due to their upper caste status. Therefore, they did not benefit from outside networks and connections as much as working mothers, and were not as able to tap into community resources. Other mothers delayed in getting an initial diagnosis (not wanting information), even if they strongly suspected their child had a disability, out of fear of knowing. Overall, the investigators found that—despite its disadvantages—the most common source of information was the family” (ibid, p. 76).

Regarding East Asia, in Wang and Michaels 2009 study of Chinese parents, one of the findings was that mothers of autistic children especially felt that they had inadequate information to facilitate their coping. The authors explained that autism is a more pervasive intellectual disability than many other conditions, and that whereas children with Down syndrome tend to have a more cheerful and friendly demeanor, children with autism can often be irritable, socially awkward and aggressive at times, making care giving tasks and relationship-building difficult for mothers (Wang and Michaels, 2006; Wang et al., 2010, citing Hastings et al., 2005; Hoffman et al., 2009).

Wong et al. (2004) noted that Chinese mothers’ greatest need was for information regarding the treatment of their child’s disability and how to make their daily lives easier. As many children had problem behaviors, parents asked for particular information on strategies to manage such behavioral problems. Another parent revealed her lack of information by stating: “I’d like to know whether all the children with mental retardation
have epilepsy or not” (ibid, p. 149). In this particular study, the children had significant developmental disabilities that would likely be permanent. However, the parents revealed that they were focusing on treatments that would bring full recovery. This may cause them to bear great expense in trying many therapies searching for a cure that would never come. Therefore, accurate information is even more important (to avoid unnecessary ‘cure’ treatments, and to set realistic goals).

As for South East Asia, Morgan and Tan’s (2010) qualitative study on Cambodian parents’ perceptions about the effectiveness of family-centered rehabilitation evidenced the importance of parents receiving adequate information about their child’s disability, and treatment possibilities, for their emotional well-being. Unfortunately, although the parents said that they highly valued family-centred rehabilitation, most had not received necessary information on their child’s disability, reasons for treatment or future outlook. One mother stated:

They haven’t told me where the problem comes from or the reasons for treatment. I just heard the staff talking together about ‘CP’ but I don’t know. The staff just help and check my child and talk with the other staff about my child’s problems, but I cannot catch what they talking about. I used to hear the word CP but don’t know the meaning of it (ibid, p. 165).

The authors noted that those mothers raising children with moderate and severe cerebral palsy were the group to receive the least information, and in fact, many were unsure about why their child had a disability. The authors posit that this may be do to staff not wanting to be bearers of bad news, or that staff may not know how to communicate effectively and simply about complex cases. The authors noted that part of the information gap may be explained by the hierarchical nature of Cambodian society, where asking questions of (or challenging) professionals is deemed unacceptable and arrogant. As one mother noted: “I am afraid to ask questions, because they might think that I am interrogating them…”(ibid, p. 165).

**Middle East**

As for Middle East, Bilgin and Kucuk (2010) concluded that many Turkish mothers—raising children with autism spectrum disorder—are quite anxious over a lack of information regarding treatment options. Mothers in Iran also noted a lack of information to help their child: “I need to know about management of myself and my child but,
nobody gives me more help and support…and they do not have new and up-to-date information about disability for me… (Kermanshahi et al., 2008, p. 322).

**Africa**
As for Africa, Hartley et al. (2005) found that there is a great amount of inaccurate information surrounding all aspects of disability in Uganda. They concluded that accurate information needs to be disseminated about the causes, prevention and treatment of disability. One example of inaccurate information is the belief that epilepsy is contagious, and so children with epilepsy are isolated needlessly. As one mother stated: “…he cannot eat with others because he has the bad disease of falling (epilepsy). We fear that he could pass the disease to his brothers and sisters” (ibid, p. 175). Another mother stated that other mothers refuse to let their children play with their disabled child, due to fear of catching the disease (epilepsy). In Uganda, the researchers reported that when mothers get information, they start to change their outlook for the better. As one mother noted, “Many families [now] accept their children and involve them in domestic chores, and family activities” (ibid, p. 176). The researchers also found that mothers were very reluctant to do any therapy on their own, out of fear of doing something wrong, but continued to wait for advice and instruction from doctors and therapists. When clear, or ambiguous information was received however, it resulted in higher stress in mothers and inhibited the coping process (ibid, p. 178). Finally, a few mothers were fatalistic in their thinking, and so did not seek out much information or therapy ideas, instead seeing the child’s disability as their “lot in life.” This was a minority though.

**Analysis**
Almost all of the articles revealed mothers’ struggles to make informed choices for their children, due to inadequate information about the disability’s causation, best treatment options, where to access services and future outlook. In many countries, the proper infrastructure was not in place to disseminate disability information, and even when mothers did possess information about the best treatment options, rehabilitation centers were few and far between, and transportation was costly. Many mothers across the studies said that the most valuable information is that which helps to improve their daily lives. Unfortunately, in some cultures like India, mothers are often intentionally left in the dark due to the paternalistic attitudes of doctors (Edwardraj et al., 2010). Other new
mothers may not want information (may delay a diagnosis), out of fear of what they will be told.

The articles also revealed that when information is ambiguous or unclear, this adds to mothers’ stress and can, at times, give them unrealistic hope. For instance, some mothers only sought-out treatments that would offer a full cure, even though their child’s condition would be permanent (intellectual disability).34 Those mothers that stayed home with their child often received the least information, due to a lack of outside connections and social networks. In these cases, the extended family was often the primary source of information. Often, such family information was inadequate and reflected society’s overall lack of disability-awareness.35

6.8 Knowledge and Skills
This category explores the idea that, the more everyone in the household has a chance to improve their knowledge and skills, the less impoverished that household will be, and the more each member will have a chance to make the most of their lives. However, for this study, ‘knowledge and skills’ will pertain to mothers’ skills and abilities in improving the lives of their children with disabilities (and thus their own lives). This category has strong links to ‘appropriate information,’ and the two categories often overlap (appropriate information being a precursor to knowledge and skills).

Asia
In terms of findings for South Asia, McConachie et al. (2000) found that Bangladeshi women who struggled to adapt to life raising a child with cerebral palsy were much more likely to come to rural or urban treatment centers to seek information and skills about how to improve the lives and independence of their children, and thus improve their own lives. In India, Edwardraj et al., (2010) found that many mothers were eager to gain as many skills possible to help their children. One mother stated, “I have enrolled in the training programme to get professional help, and to see how other parents are handling

34 Note that even with correct information, mothers may still need unrealistic hope as a coping mechanism for a time.
35 Many researchers, therefore, recommended public awareness campaigns to update citizens on disability issues.
their child” (ibid, p. 742). Learning from other more experienced mothers was seen as something quite valuable, even for the social interactions. An interesting finding in a Pakistani study found that mothers raising a child with disabilities were actually empowered by being allowed to leave their traditional roles in order to advocate and find appropriate supports and services for their children (Yousafzai et al., 2010). However, the other disempowering aspects of their lives outweighed this benefit.

In Bangladesh, Maloni et al. (2010) noted that having a good education (knowledge) is positively correlated with mothers’ search for, and use of, disability services. Since over two-thirds of women in Bangladesh are illiterate, many do not have the means to search for appropriate services. Also, the researchers found that many mothers were lacking knowledge about how to carry-out home therapy, resulting in fear and a failure to follow-through with the doctors’ instructions. As one mother noted: “…The doctor also suggested some therapy, some exercise but I am very much afraid… because I’m not sure how to do that or if my child could get hurt (ibid, p. 5). Another mother had positive things to say about rehabilitation staff: “Yes, I think is good because they train me for 14 days and I also practice in front of them. They correct me so I hope God will help me with the help of that service, and I will do it at home” (ibid, p. 5). The investigators also noted that after receiving education about their children’s disability, mothers were able to create more realistic therapy goals for their children.

As for East Asia, Wang and Michaels (2009) found that Chinese parents raising children with severe disabilities expressed a great lack of knowledge about their children’s disabilities, and stated that they needed training in how to adapt their parenting skills to meet the new demands of daily life (i.e., how to address challenging behavior). In McCabe’s (2008) study of Chinese parents raising children with autism, one parent said, “I still need to learn and grasp more and better methods and strategies for teaching children with autism. I need exchange with autism parents and communication with experts/professionals, to set up a bridge of ‘exchange of needed goods’ (hutong you wu) (ibid, p. 309). In Wong et al.’s 2004 study, parents also emphasized the need for more training sessions, so that parents could better meet their children’s needs at home.

In South East Asia, Cambodian parents raising children with mild to moderate disabilities
wanted to be very involved in the rehabilitation program, saw themselves as experts on their children’s disability, and wanted all the information and skills possible. In contrast, those parents with children with more severe disabilities were not as involved, and did not want as much collaboration. They reported feeling “ill-equipped” to help with the complex care their children needed. Overall, these parents reported feeling more comfortable with rehabilitation staff making the decisions. Investigators noted that most mothers lost hope in the collaborative process and goal setting when their child did not meet the goals set (i.e., walking independently). The authors emphasized that, to avoid feelings of helplessness and despair, staff had to help the parents and child set realistic goals, and give them a firm understanding of the child’s condition so that they could set realistic goals based on accurate information (Morgan and Tan, 2010).

**Middle East**

Some Kuwaiti mothers expressed concern that the home-based program for rehabilitation was not clear, and they were not sure about how to do the exercises correctly. They feared injuring their child and felt ill-prepared to carry-out the exercises and treatments by themselves (Raman et al., 2010). As for Turkey, 46.6% of mothers reported a lack of knowledge about their child’s autism and proper care (Bilgin and Kucuk, 2010), and in Iran, mothers reported that they did not have adequate knowledge to physically and emotionally care for their children (Kermanshahi et al., 2008).

**Africa**

In Uganda, the authors noted several communication breakdowns between mothers and children with communication disabilities (particularly deafness), due to lack of knowledge and training for both parties in sign language. The findings also revealed that many mothers wanted more skills in helping their children, (thereby helping themselves indirectly by decreasing their stress levels) (Hartley et al., 2005).

**Analysis**

All of the developing world articles were quite similar with respect to this category. Generally, mothers are greatly lacking the knowledge and skills to improve the lives of their child with disabilities (and thus their own lives). It was found that, in general, the more mothers were struggling to cope with raising their child, the more they would seek
out additional skills. Mothers particularly emphasized the benefit of learning from more experienced mothers who have a child with a similar condition to their own child’s. As for specifics, mothers acknowledged their incompetence surrounding home therapy (i.e., not knowing how to do it properly, afraid of hurting their child if do something wrong, etc.), and they asked for more help in handling their children’s problem behaviors.

In the studies overall, there was one contradiction between level of maternal education and the seeking out of knowledge and skills. In Bangladesh, for instance, mothers with more education searched for, and used, disability services more than less educated mothers (Maloni et al., 2010). However, in India, some educated mothers did not seek out services due to the stigma attached to disability, and due to the fact that a disability reflects badly on the whole family (Edwardraj et al., 2010). These differences warrant further investigation.

Finally, those mothers with children with the most severe disabilities often feel the most ill-equipped to care for their children. In Cambodia, however, these mothers were the most reluctant to gain more knowledge and skills, preferring to leave the complex care to the professionals. On the other hand, Cambodian mothers with less severe disabilities wanted all of the knowledge and skills possible (Morgan and Tan, 2010). This surprising trend should be researched more in Cambodia and in other countries. It may be that a sense of overwhelming hopelessness surrounds some mothers (particularly the ones with the most disabled children), making it seem futile to learn additional skills.

6.9 Defensible Life Space
Friedman identified defensible life space as a family’s ability to keep living in the place they call home. A forced moved is always disempowering. Only two examples were found among the 39 studies that relate to defensible life space (both from Asia). However, a few African studies about disability in general, such as Chirwa (2011), note that it is not uncommon for a family to be banished to the outskirts of a village once it is known that they have a child with a disability (particularly if it is thought to be a contagious disability, like epilepsy is believed to be).

As for the Asian examples, in Edwardraj et al.’s 2010 study, one health worker described
what an Indian woman’s situation can be once she bears a child with a disability: “The woman has no future…The woman is sent back to her home while the husband remains” (p. 742). In other words, she loses her physical home and sense of belonging due to the fears, ignorance and negative attitudes of others. In a Chinese study, McCabe et al. (2007) reported that one elder male relative argued that the family must move far away from his work colleagues, as the shame would be too great to let the child with disabilities grow-up alongside his colleagues’ typically-developing children (p. 43).

6.10 New Category: Culturally Based Attitudes and Beliefs

From the data analysis, another base of social power has become evident, one that Friedmann has failed to consider. This new social base deals with the ability of culturally based attitudes and beliefs to contribute to one’s empowerment/disempowerment. The findings below show how negative societal attitudes can indeed lead to disempowerment for mothers raising children with disabilities in the developing world.

Asia

In India, Edwardraj et al.’s 2010 study, mothers particularly emphasized how negative societal attitudes impact their quality of life. The authors found that cultural and religious beliefs reinforced negative attitudes towards disability, with the result that mothers had little support from family, friends or society. One prevalent belief is that parents (particularly mothers) must have done something wrong—in a past life, or during pregnancy—to deserve having a child with disabilities. Even health workers believed that mothers must have done something wrong during pregnancy (i.e., ate the wrong foods, argued too much), and thus had less sympathy, believing the condition had been preventable.

Several teachers in the study echoed this teacher’s sentiment: “Maybe the parents have done something wrong. They should turn away from their sins and get closer to God” (ibid, p. 744). In this study, health workers confirmed that mothers are usually blamed, and they suffer consequences such as being socially ostracized, being verbally abused by the extended family (particularly the in-laws), and having the husband leave in some cases. Similarly, teachers blamed the parents and held them responsible for their child’s lack of ability in school, claiming that the child did not receive enough stimulation at
home. The authors note that some teachers attributed “the problem to ‘bad character’ in the parents. They believed that the child’s inability to do well at school was a bad trait inherited from parents rather than a skill deficit because of ID” (ibid, p. 741). However, those teachers that had actually spent time with child and family attributed the child’s lack of ability to medical factors, and thus had more sympathy and understanding. Even some of the mothers blamed themselves and felt guilty, wondering what they could have done to avoid the disability.

In another Indian study, Peshwaria et al. (1998) found that such self-blame and internalizing negative societal and familial comments hindered mothers’ coping abilities more than fathers.’ The investigators explained that this may be due to mothers’ need to rely on others more for help in the community; thus, they feel it more personally when the child is rejected. The authors also noted that mothers found “faith in God” to be a huge facilitator in coping when other help was not forthcoming (i.e., from family or friends). The authors emphasized that negative societal attitudes can be psychologically damaging to Indian mothers, and that extended family may feel that the child’s disability reflects badly on the whole family.

As for beliefs about employment, Kalyanpur and Gowramma (2007) noted that Indian mothers of upper-caste raising an adolescent were most concerned with him/her finding employment, but held the belief that manual work was not appropriate for someone of their caste. Therefore, even though manual work may have suited the mental capacities of the adolescent more, it was ruled out due to the shame that such a job brought. Mothers kept searching for other ‘more suitable’ employment for their adolescents.

In Bangladesh, although many mothers recognized the biomedical causes of disability on one level, many still attributed it to possession by ghosts, the activity of evil spirits, or a mistake during pregnancy. Many mothers held these competing beliefs simultaneously. In general though, the most common reported cause was maternal behavior, such as a sin or a fall at some time during the pregnancy. One mother said: “… maybe I am doing something wrong, doing something to God, so he gave me this child. Then I also think that I am not doing any sin, I am being honest, but maybe in my unconscious mind I am sinning” (ibid, p. 4). As for those mothers who believe in reincarnation, they were less
likely to seek treatment for their child, as they saw the condition as temporary (Maloni et al., 2010, p. 2, confirming findings in a study by Danesco, 1997). In addition, many mothers who did not believe in traditional treatments as much as biomedical ones still felt pressured to seek out traditional healers by elders in the household. They felt that they had to abide by the elders’ or in-laws’ wishes, incurring much cost for something the mothers themselves did not believe in. Finally, Maloni et al (2010) also demonstrated that negative societal attitudes can even cause Bangladeshi mothers to see their own disabled children as less human than other children, as evidenced by this mother’s statement: “Every mother wants their child to be educated, grow up as human being. I also want it. I want it. I want my child to grow up as human being not as disabled” (ibid, p. 6).

In a different study, McConachie et al. (2000) discovered that since Bangladeshi society values boys more than girls, boys with cerebral palsy were much more likely to be initially taken for rehabilitation than girls (particularly in rural areas), and much more likely to be brought back for ongoing therapy. Therefore, girls with disabilities are likely to suffer more and perhaps die earlier than boys.

In Pakistan, Yousafzai et al. (2010) found that where women typically experience restrictions in freedoms and movements, many mothers felt empowered by taking-up an advocacy role for their children. They were able to move beyond traditional boundaries in order to seek out beneficial treatments and education for their child. One mother stated, “Because of my child, my husband lets me seek whatever I think is necessary for our child” (ibid, p. 6). Despite this benefit, there were many negatives in raising a child with disabilities. For instance, the study found that mothers’ self-perceptions were influenced by societal stigma; their identity in the community was first and foremost a mother of a disabled child. Also, many negative attitudes came from relatives who also blamed the mother and saw the disability as a “woman’s punishment.” This made daily lives difficult for mothers who often had to live with extended relatives. As one mother states:

On the one hand my son is not well, and on the other I receive no support from my husband. Rather he blames me [for my son’s disability] and says I should ask for forgiveness from my sister in law, mother in law and father in law. They say he [my son] is a punishment for my sins (ibid, p. 5).
Another mother complained that her mother-in-law kept pressuring her to have another baby soon, even though all of her time and energy was spent caring for her child with disabilities. The reason given was that her son’s name had been tarnished by having a child with disabilities, and that he needed to redeem himself by having a healthy baby (ibid, p. 5). Other mothers stated that people have told them that they must be bad, with malevolent intentions, or else they would not have had a child with a disability.

Some Pakistani mothers coped by thinking positively and by seeing their child as a symbol of strength rather than weakness. The word the group of women chose to represent their lives was ‘azmaish’ [a test of endurance in life]. They said that term implies strength, and that God perceives them to be strong enough to care for a child with disabilities (ibid, p. 5).

In China, several researchers have found that it is not uncommon for mothers to hide children with disabilities in the home, especially during the early years, in order to “save face” (Lam and Mackenzie, 2002 as cited in Wang et al., 2010, McCabe, 2007). As one mother noted, “It is not a good thing to have a child like this…I am afraid of letting others know that I have such a child” and “I don’t tell others about my child. I’ll be looked down on because of the child” (Wong et al., 2004, p. 152). Some parents would send their children far away to rural areas, to be cared for by grandparents, to avoid stigma, and perhaps out of financial necessity (McCabe, 2007). Other mothers were fearful to send their children to school, due to fear of stigmatization (Liu, 2003, p. 95 as cited in McCabe, 2007).

McCabe (2007) said that within families, there is often a feeling of shame accompanying a child with a disability, as it is seen as the result of something the parents, and often the mother (or her side of the family), have done, and thus they are blamed (2007, p. 40)

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36 Yet parents still affirmed that they wanted the best for their children, and so there was a tension among parents (not wanting to feel embarrassed or ashamed, yet wanting their children to have the best of everything).

37 McCabe noted that, “Almost every family interviewed for this study mentioned their fear of being discriminated against if others found out that their child had autism (or was in some way ‘different’ from typically developing children)” (p. 43)
citing a study by Holroyd, 2003). Mothers felt that such beliefs stemmed from a lack of information in society about disability and its causes. Wong et al. (2004) found self-blame to be prominent among Chinese mothers.

Other Chinese studies emphasized parents’ fears about the child’s future. Wang et al. (2010) found that pessimism about the child’s future was closely tied to: the failure of the child to perform academically (something of great value in China), the extremely competitive nature of China’s formal employment sector (knowing their child would never compete), and the underlying realization that their child would not be able to care for them in their old age. The authors note that pessimism among Chinese parents (raising children with autism or other significant developmental disabilities) is greater than western levels, perhaps due to the aforementioned factors, and due to the fact that studies have shown that Chinese society—and mothers themselves—have more negative attitudes towards those with severe intellectual disabilities than those with minor disabilities (Huang et al., 1998 as cited in Wang et al., 2010).

Wang et al. (2010) noted that high levels of family stress were, in part, attributed to the Chinese value of harmony. In China, if a family is not united—not living harmoniously—it is a source of shame, and the perceived cause of many social ills. Mothers perceived more family and parent related stress than fathers. In fact, Chinese families try and solve problems on their own to avoid stigma. For this reason, Qian et al. (2002, as cited by Wang et al., 2010) note that many families take their disabled children far away to try and get help (instead of ‘losing face’ through accessing local services).

As for South East Asia, researchers in Cambodia found that mothers displayed little fatalism about their children, despite Cambodia being stereotyped as a fatalistic culture. Indeed, mothers kept seeking active treatments for their children and expected improvement (Morgan and Tan, 2010, p. 166). Family and friends in the villages believed mostly in the traditional causes of disability (i.e., karmic destiny and possession by spirits), but mothers questioned this commonly held belief (Morgan and Tan, 2011, p. 4). Some mothers also exhibited self-blame resulting from a lack of information. For instance, one mother said, “I don’t know. I want to ask whether my child’s problem
comes from me leaping from a tree when I was two months pregnant. Some people say it’s because I had looked at the full moon…” (Morgan and Tan, 2011, p. 5).

**Middle East**

In Turkey, although most mothers understood the biomedical causes of their child’s disability, they still attributed the cause of the disability most often to God or Allah (i.e., “fate” or “God’s plan for them”). Sometimes though, such religious attitudes fostered a fatalistic attitude. For instance, one mother said: “We have recognized my child’s developmental delays before he was one-year old. We believed it was our Fate; it was God’s choice for us. Therefore, we didn’t take our child to the doctor” (Diken, 2006, p. 13). Some mothers even blamed themselves for their child’s disability, or were blamed by others (i.e., by holy men saying they were struck by an Evil Spirit for not performing certain rituals before leaving the house) (*ibid*, p. 13). As for self-blame, one mother said: “When a mother becomes pregnant on either a Monday or Friday, especially Friday, the child will have a disability when s/he was born” (*ibid*, p. 13). Several parents concurred that getting pregnant on holy days would likely cause a disability. Another mother said, “I was too sorry about my neighbor’s child, who had autism, during my pregnancy. I think that might be one of the causes of my child’s disability” (*ibid*, p. 13).

In Bilgin and Kucuk’s 2010 Turkish study, a lot of the mother’s expressed fatalistic attitudes and resignation, seeing their situation as their destiny and lot in life. Sometimes, fatalistic talk was combined with words of despair for this life but hope in the next (i.e., “Living with an autistic child has no benefit in this world…But, I believe it will have a lot of reward in the afterlife”) (*ibid*, p. 94). Finally, 30.2% of mothers in this study noted the lack of acceptance of their children by society as quite problematic. Still much stigma surround autism in Turkey, so mothers struggle more, and may be embarrassed to seek out services due to stigma, as in other cultures (Dyches *et al.*, 2004 as cited in Bilgin and Kucuk, 2010). Uskun and Gundogar (2010) also found that negative societal attitudes about disability lead to fewer social interactions for Turkish parents and their children. So cultural attitudes and social networks (as bases of social power) are strongly intertwined.

In Kuwait, Raman *et al.* (2010) found that most mothers turned to Allah to try and explain their situation as a means of coping. Many described their situation as: “fate,”
“Allah testing them/challenging them,” “Allah entrusting them with a special mission in life to care for this child,” etc. (p. 55). Despite these religious beliefs, and despite some having a fatalistic attitude, all mothers (especially those who saw their situation as a challenge from God) were motivated to take their children to rehabilitation to improve their functional capacity. Many mothers also held positive attitudes as a means of coping. For instance, one mother said: “In my opinion, a disabled person has achievements and more creativity than normal people do” (ibid, p. 54). The authors noted that this belief was shared by all participants (ibid, p. 54). The participants also felt that negative attitudes about disability persisted in society, even among family and friends. They felt that others could not see the many abilities of their child, just the things that the child could not do, or struggled to do. In this study, one unique feature was that parents focused on the dangers of “pitying” people with disabilities instead of just treating them normally (ibid, p. 54).

In Iran, most mothers relied the most on spiritual/religious coping, believing that they were chosen for a certain reason to raise a child with a disability, and thus would be rewarded in the next life (Kermanshahi et al., 2008). The authors emphasize that: “Beliefs within the Iranian culture are that one of God’s most important tests is illness or any disability of a child. If parents are patient, God loves them more and their lives will be more satisfying” (ibid, p. 320). A 2008 study out of Iran by Dehnavi et al. found that mothers of children with Down syndrome are at risk of internalizing the stigma surrounding their child’s disability. Since being an older mother is a known risk-factor for birthing a child with Down syndrome, these mothers in particular were at risk for self-blaming and/or social avoidance behaviors.

In Jordan, women found great solace in religion, and it was cited as their main coping mechanism. Most mothers saw having a child with disabilities as part of their destiny, a test from God and an opportunity to learn patience and perseverance. The mothers still thanked God for what they were given. In terms of causality, most of the Jordanian mothers claimed witchcraft was the culprit (McConkey et al., 2008).
**Latin America**

In the Guatemalan study, Saetermoe *et al.* (2004) found the negative attitudes still persist towards those with disabilities. In this study, mothers were parenting adolescents with disabilities, and some were searching for suitable employment for their adolescents. However, the prevailing attitude in Guatemala is still one of charity towards the disabled; hence, many are deemed unsuitable for work by employers. The authors also found that mothers sometimes internalized negative societal attitudes; as a result, some failed to send their disabled children to school out of embarrassment (Couch *et al.*, 1991, p. 47 as cited in Saetermoe *et al.*, 2004, p. 1037). Other mothers were distrustful of others’ intentions towards their child and overprotective, trying to shelter their adolescents from the cruelty of society by keeping them indoors more often (*ibid*, p. 1043). On the positive side, the authors did emphasize that many mothers try and cope by focusing on the positive and emphasizing their adolescents’ strengths. For instance, if their child had only a serious physical disability and no intellectual impairment, parents saw this as a blessing and focused on their adolescents’ strong minds. Also, many coped through religious beliefs, seeing their child as a gift from God and an opportunity more than a burden. Indeed, many believed that they were ‘chosen’ by God to have a child with disabilities, and that God was going to make them stronger through this experience.

**Africa**

In Uganda, the investigators noted that negative societal attitudes manifested primarily as rejection of the child (by teachers and schools refusing admittance, by family members and by friends), and resulted in loneliness for the child and mother (Hartley *et al.*, 2005, p. 174). Several informants mentioned that some members of the community still believe that children with disabilities are “objects of shame,” and thus should be hidden. As for the disability’s causation, many parents attributed it to God’s will, witchcraft or angry ancestral spirits. In a study out of Nigeria, a full 35% of mothers attributed the cause of disability to evil spirits or witchcraft, while only 10.4% believed in natural causes (Abasiubong *et al.*, 2008).38

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38 Note that in the same study, 17.9% of mothers claimed the disability was caused by the diabolical powers of their in-laws! (Abasiubong *et al.*, 2008).
In Hartley et al.’s Ugandan study (2005), when some mothers viewed their child’s disability as their God-ordained fate, they had a fatalistic attitude: “Well, it is what God has chosen for us. I am hurt, but what can I do?” and “We knew the child had become deaf and that was God’s will. We never bothered to seek for an explanation of the cause of the problem from spiritualists…” (ibid, p. 177). In some cases, this fatalistic attitude has resulted in mothers not seeking out therapy or further medical care.

Finally, it should be mentioned that beliefs were not only disempowering but empowering at times. For instance, many mothers tried to see their children’s abilities, instead of their disabilities. As one mother said, “I look for food and prepare it for [the child] to cook. She sits by the fireplace...she can put fuel in the fireplace easily” and another “She goes to the well with others... she does work...she digs, she peels potatoes” (ibid, p. 177).

**Analysis:**

As demonstrated above, cultural beliefs and attitudes were, for the most part, very influential in disempowering mothers. Although this is true in this particular context (mothers raising children with disabilities), it may also be relevant with respect to poverty in general in the developing world. Thus, Friedmann’s model may be incomplete.

Overall, cultural beliefs and attitudes about disability in the developing world are largely negative and reinforce the discrimination that disabled individuals already face. Due to the stigma, myths and stereotypes surrounding disability, mothers and children find themselves isolated and on the margins of society. Indeed, it is thought that disability is a result of spirit possession, a curse, the mother’s sin or wrongdoing, or failing to appease ancestral spirits. Some of the studies showed that, when mothers held a fatalistic attitude about their child’s disability, some did not seek out help or services. Others did not seek out help if they believed in reincarnation, feeling that the child’s condition was only temporary (i.e, some mothers in Bangladesh). Of course, this has ramifications for both the mother and child’s wellbeing in the here and now. Sadly, very few studies highlighted the numerous gifts that children with disabilities can bring to their homes and communities (i.e., fresh insights, creativity, a knack for uniting people, laughter). Indeed, it was quite disheartening to see the pervasive negativity in the articles as a whole.
Many studies in various countries evidenced self-blame on the mothers’ part, perhaps because they internalized society’s negative attitudes, or because a lack of information on disability causation left them no room but to speculate about their own role in the disability’s formation. Therefore, beliefs and attitudes that are disempowering do not only come from external sources, but sometimes from within the mother herself. In a way then, she contributes to her own disempowerment. Internalizing negative societal attitudes was particularly seen in Iran (among older mothers of children with Down syndrome, who blamed themselves for having a child when older) and in Guatemala. The epitome of internalizing negative societal attitudes was seen in a Bangladeshi study where a mother said that she wanted her child to “grow up as human being, not as disabled” (Maloni et al., 2010, p. 6).

In several countries, like China and India, feelings of shame were particularly strong among families with a disabled child. For instance, several of the Chinese studies noted that children with disabilities were sometimes hidden from view, or kept from attending school, so that parents could “save face.” In Uganda also, children with disabilities were sometimes locked away out of embarrassment. This pressure to hide a human life is in itself disempowering, as mothers are robbed of the chance to celebrate their children (children who probably have many gifts to offer, as well as limitations). Also in India, there was shame if an adolescent with disabilities from an upper-caste were to do manual labor (Kalyanpur, 2007). Therefore, both the adolescents and mothers were disempowered, as the adolescents could not find work appropriate for their intellectual level and ability, and mothers, because they refused to let their children do manual work and contribute to the household economy.

Finally, the importance of religious beliefs should not be underestimated. In the developing world, particularly in the Middle East, mothers used their faith as a coping mechanism. They saw Allah as choosing them for a special task, testing them now for a reward in the afterlife, and giving them extra strength to care for their child. Indeed, some women began to be empowered by their situation and beliefs, summoning strength they did not know they had. Therefore, attitudes and beliefs can also be a source of empowerment, although most of the articles evidenced the opposite.
In comparing the 39 articles, it was surprising how similar mothers’ experiences were, irrespective of their nationality. Certainly, there were differences (i.e., Chinese mothers seemed to suffer more stigma than those from other nationalities, Middle Eastern mothers relied on their faith in God/Allah more as a coping mechanism, etc.), but by and large, their situations were strikingly similar. Indeed, a mother raising a child with significant disabilities in Uganda would have many similarities in experience to a mother in Iran or Guatemala. Although some studies mentioned mothers’ positive attitudes, religious coping and connections with other mothers as empowering experiences, all of the studies underscored aspects that primarily disempowered these mothers. Also of note is the fact that—regardless of the geographical region—negative attitudes and beliefs about disability (and the resulting stigma) were quite prevalent in most studies, as was the emphasis on the importance of mothers’ physical and emotional well-being (the mind and body being instruments of work and livelihood). These two bases of social power, along with social networks, were the areas discussed most in the articles. Finally, only one study highlighted that mothers were empowered by being able to seek out the best services and care for their child, thereby having greater freedom of movement than society normally permits women (Yousafzai et al., 2010).

As for Friedmann’s social (dis)empowerment model, it has proven to be quite helpful under normal conditions of analyzing poverty in the developing world, and it was also very applicable in shedding light on these mothers’ situations in raising a child with a significant disability. However, Friedmann did miss one important element in his multi-dimensional understanding of poverty: the cultural beliefs and attitudes that either empower or disempower an individual. Furthermore, many of the articles evidenced that these beliefs and attitudes are not always external (at the societal level), but can be internalized (i.e., when mothers begin to believe societal messages that they are to blame, or that children with significant disabilities have nothing to offer this world). It was also seen that culturally conditioned beliefs are not always disempowering but sometimes empowering (i.e., when mothers say that their faith in God has strengthened them). Overall then, Friedmann’s model was helpful but insufficient to understand the impact on
mothers’ lives of raising a child with significant disabilities.

Regarding future research, due to the paucity of studies in Africa and Latin America, future research warrants greater focus on these regions. Furthermore, more studies should be done on the impact on poor mothers in relation to wealthy mothers. Although some of the 39 articles focused on rural mothers (who are typically poor), or on mothers who could afford to attend the expensive programs at the Autism Institute (in China), most of the articles simply looked at mothers in general raising a child with disabilities, without much detail given on their socio-economic status. Part of the problem is that the “developing world” is so vast, and that there is much socioeconomic stratification even within countries, provinces and cities. Because lifestyles are often so different in cities compared to rural villages (i.e., with traditional attitudes and beliefs more prevalent in the latter), more studies should be done with a distinct urban-rural comparison. Also, many mothers in various countries highlighted the importance of parent-to-parent support groups for their emotional and social wellbeing; therefore, additional studies should be done on how mothers fare in a parent-to-parent support group versus those who do not belong to such a group.

Several other points of interest from the articles that warrant further exploration are: the connection between disability and poverty, the impact of raising a male or female child with disabilities on mothers, the impact of the number of children in the household on maternal stress (i.e., are more children better or worse, and is this dependent on whether there are older children to help the mother?), and the question of whether maternal fatalism spurs (or hinders) intervention seeking. Furthermore, more research needs to be done on the connection between the child getting older and maternal stress levels. Some studies suggested that mothers cope better as the child ages and have less stress (Khamis, 2007), while others suggest that the opposite is true (Wang et al., 2010).

In addition, research has to somehow tap into mothers who have not come for therapy or services. Most of the mothers in the articles had already sought out treatment for their children, and the researchers found them at rehabilitation or disability centers. Therefore, the studies are not representative of all mothers of children with disabilities, only those worried enough, and those having enough information and resources, to seek and find
help. If these women are disempowered, what must it be like for the many other mothers who do not seek out help? Most researchers admitted this limitation in their studies.

Finally, as development dollars are limited, and since it will be difficult to convince many aid organizations of the worth of spending money on a minority population of children with disabilities and their mothers, it is important to put aid dollars into those areas that the 39 articles indicated are most in need of attention. As aforementioned, improving mothers’ physical health and emotional wellbeing (instruments of work and livelihood), combating negative societal attitudes and beliefs about disability, and improving mothers’ social networks, are the three most important areas to address.

To start, some simple and relatively inexpensive strategies can be adopted. First of all, parent-to-parent support programs should be set-up (run and organized by parents of children with disabilities) so that mothers have a means to share their stories and learn from each other. Perhaps this could lead to shared child-care responsibilities to give the mothers more free time and rest. Secondly, information campaigns should be set-up about disability to dispel some of the myths and stereotypes that surround it (in particular the notion that mothers have sinned and are to blame), and to show that those with disabilities have much to offer society. Thirdly, respite care needs to be offered to these mothers (by family, friends or by subsidized personal support workers) to give them the physical and mental rest that they so desperately need. These three strategies could go a long way in increasing the quality of these mothers’ lives, and thus the lives of their children. Development efforts to help these mothers’ need not be overly costly, yet they have the potential to empower those who need it most.
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Disability, 34(1), pp. 10-16.


**Unpublished Journal Articles:**


**Books and Chapters in Books:**


### III. On-Line Sources


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### IV: International Organization Documents, Conference Reports


