

A Family Narration of Disability Experience in Iran
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Abstract: Focusing on Mohsen Hosseini Taha, a person with cerebral palsy, and his family, this research explores the social and mental consequences of having a member with physical disability on a typical Iranian family. The oral narratives used in this research have been collected in a series of in-depth interviews with Mohsen, his parents, and his only sister, in 4 sessions or 10 hours of face-to-face interviews. The analysis of the interviews addresses several questions: How was Mohsen's disability initially diagnosed and what were his parents' first reactions? What have been the social obstacles facing Mohsen's family's efforts to practice a routine life within Iranian society? How has Mohsen's disability affected his family's life socially and mentally throughout the years? Finally, how well do core concepts of Western disability studies apply within a typical non-western family? The real names of the participants have been used with their permission.

Keywords: disability, family, Iran

“...And the tragedy begins with his/her gradual isolation from the society. The tragedy begins when a person with disability transfers to a machine with no rights to have fun, to love, and to live like the other individuals. The tragedy happens in a society who treats persons with disability like unhumans. Our life tragedy is made by our society, not by our disability...”
-Mohsen H. Taha

In the Family's Words

There is no exact number of people with disabilities living in Iran; however, according to the latest report of the State Welfare Organization of Iran (October 2012), about 10% of the total population has disabilities that would yield an estimated number of 7,500,000 individuals. By considering the families who have at least one member with disabilities, the number of Iranians who are dealing with disabilities, directly or indirectly, increases up to 25,000,000 individuals (State Welfare Organization of Iran, 2012).

Mohsen Hosseini Taha was born ironically in 1981, the International Year of Disabled Persons, in Tehran-Iran, and was diagnosed with cerebral palsy at the age of three. For more than thirty years the Tahas, a middle class family living in Karaj (near Tehran, the capital), have been dealing with the disability of their son, Mohsen. I remember the first day I met Mohsen waiting for me early in the morning at the newspaper office. I could barely understand what he tried to say until he decided to write down what he wanted. I could eventually read the nearly illegible but impressive handwriting of a young boy with a severe physical disability who wished to collaborate with the disability page of *Ettela'at* newspaper. He had brought samples of his writings which sounded strong enough to hear immediately a “yes” respond from me, but I had to check first with my boss before giving him any promises.

A week later, Mohsen started working for the disability page of *Ettela'at* newspaper under my supervision. For Mohsen, this was the dawn of his entry into the realm of the Iranian

media professionally; he started working for other newspapers as well. Mohsen and his family soon became a part of my articles on the disability experience in Iran. As a journalist dedicating her career mostly to disability issues, I have published several interviews with the Taha family in *Ettela'at* newspaper, and have combined and translated them into English for this article. The interview sessions have provided over 10 hours of narrative data from which to explore the Tahas' perspective.

An exploration of the Tahas' views shows how at least one Iranian family has experienced a disability, suffering not primarily from their child's disability, but from the way their society has treated them for having a disabled child in the first place. Their experience also shows how attitudes in many traditional societies may not distinguish physical and intellectual disabilities, with both groups being denied their basic human rights. Finally, the Tahas' experience provides an opportunity to analyze how familiar concepts of Western disability studies (e.g., the contrast between social and medical models of impairment and disability) can be observed in practice within the family context of a developing country such as Iran (International Monetary Fund, 2012).

Mrs. Taha (Mohsen's mother): "It was actually during the Iraq-Iran war when I was taken to a hospital, after hours of delay, to deliver my baby. At that time, most of the ambulances were either sent to the borders or at the service of the air-attacks' victims in Tehran and other cities. So, our son, Mohsen, was born with hours of delay. As an infant in his early weeks, he showed no signs of disability; yet, I remember, from his early months he could not grab his toys or crawl. Since my husband and I had raised another child (our three-year-old daughter, Mahbubeh), we were experienced enough to find out that our son's growth did not look natural. Then we started taking Mohsen to different doctors; most of them assured us that our baby was healthy and we, "the very young parents," should not be so "sensitive" to our son's "naturally-delayed" reactions."

"Mohsen was 3; his naturally delayed reactions had not vanished, but rather were aggravated with time. Eventually, a doctor diagnosed that our son was born with cerebral palsy, a physical disability that affects body movement. It was so shocking for us, because we had no disability background in our families, and expected to have a healthy child... So shocking, disappointing, and unbelievable... Our first questions were: "how to tell the truth to our families, to our parents, to our siblings, and especially to our three-year-old daughter. What would be their reactions to Mohsen's disability? Would they accept it? Would they love Mohsen?"

"It took several months to admit our son's disability. We started gathering medical information, and found out that Mohsen needed medical interventions, such as physiotherapy and speech therapy, to help his movement limitations, but we were not able to do them permanently, not only because of the expensive bills we had to pay for each session of therapies, but also because of Mohsen's resistance. The more he grew up, the more he disliked therapies that imposed too much pain on his thin bones and stiff muscles. Every session of physiotherapy ended up with his screaming and begging to stop those torturous therapies."

Mr. Taha (Mohsen's father): "For four years after Mohsen's birth, I was an undergraduate student and simultaneously, an employee. I had to manage my time, from early in the

morning till the evening, to go to work first and then to school. So, I could not allocate much time to my family, especially to my kids. I recall most of the nights when I was back home; they were in bed before I could even give them a goodnight kiss. After graduating in 1985 as a History major, I found more time for my family, and started taking my 4-year-old son to physio and speech therapy. As my wife mentioned, we had to dedicate a big budget for Mohsen's rehabilitation while the Iraq-Iran war (1980 - 1988) had affected Iranian families economically, and the situation was typically worse for families, like us, who had a person with disability in need of special care and therapies. We had to struggle not only to survive a ruinous war, but also to take the best care of our children."

Mrs. Taha: "Shortly after Mohsen was diagnosed with cerebral palsy, we decided to publicize it. As I said before, it seemed so difficult to us... It was like revealing an unpleasant secret... I think we were so fortunate that our families could understand the situation. They accepted Mohsen kindly and even encouraged us to do whatever he needed to get better. Like us, they were also hopeful that by the help of therapies, our son would find his ability to walk without braces and to speak more clearly."

"From the first years, it was obvious that our biggest problem was located outside of our family, with the people in the streets, even with some friends, relatives and neighbors. Most of them used to show us different unfriendly faces reflecting their unpleasant feelings, from absolute empathy to hatred; from over emotional expressions to cursing us for having a disabled child. Some people in the streets even put coins in the hands of my son as if he was a beggar. To them, disability equated with begging. Some people thanked God 'for being healthy, and not being like this poor handicapped boy' when they passed by Mohsen. It is still the same... We are getting used to these reactions."

Mahbubeh (Mohsen's sister): "Though I was only three years old when Mohsen was born, I could understand that my little brother needed my help. I started acting like an older sister to him from my early years. In fact, I became mature so early and too quickly... He obviously had attracted our parents' total care and attention, but rather than being jealous, I could understand Mohsen's situation. He was, and still is, the loveliest person in my life whom I used to take good care of. I knew how to play with Mohsen, how to feed him, how to teach him to pronounce words... Mohsen could not utter words clearly, and it was so heart-breaking for me. This made me to try to help him more."

"I think Mohsen brought a kind of unity to our family. After his birth, we had got one big common goal: to improve Mohsen's quality of life. My brother also brought us the necessity of a new attitude. In traditional societies, like Iran, disability is attached with grief and shame for the individual and his/her family. But our parents taught us how to practice thinking the opposite of the mainstream... to think the way that seems right, not the way that the society tried to dictate to us... I think we would never be non-mainstream if Mohsen were not disabled. Well, I cannot deny our social difficulties, our pain to see segregation, inequalities, denials and ignorance that all people with disabilities receive in our traditional society, but it was only one face of the disability coin; its other face was the unity, love, intimacy, and new attitude that Mohsen gifted us."

Mr. Taha: “At the age of 7, Mohsen’s physical disability was obvious throughout his body and speech. His cerebral palsy impeded his walking easily or playing like the other kids. He could not talk clearly either; however, his IQ was above the average. Anybody who knew Mohsen would agree that he was more mature and smarter than his age.”

“In 1988, there were a handful of special schools for the students with disabilities in Tehran. At that time, nobody could even imagine that a child with physical disability was able to attend regular schools and find a place among non-disabled students. So, our decision to register Mohsen in a regular school was an unusual one; a brave action that predictably led to objections or resistance from those who were attached to the traditional understanding of ‘dis’ability.”

“I recall the first obstacle was presented by the Education Ministry experts who asked us to prove our son’s ‘mental health and ability.’ After taking a set of time-consuming examinations and passing the IQ tests successfully, Mohsen could receive The Special Education Organization experts’ approval to be registered in a regular school. But the next hurdle was made by the principals of regular schools who were resistant to accept a student with physical disability. Even though they had talked to our son in person and had seen The Special Education Organization’s reports on his mental abilities, they still rejected Mohsen. Eventually, the principal of Yaaser elementary school admitted him.”

“Mohsen will never forget the first day that he entered the school. All of the students and the teachers were just staring at him; the kind of looking that, of course, was/is familiar to us. His teacher who knew that Mohsen had passed different tests, decided to give him an exam about elementary pre-school concepts to make sure that ‘this disabled student’ was qualified to stay at a regular school. After Mohsen passed that exam with a high grade, he received applause from his teachers and classmates who were incredulous at the abilities of a ‘stammering staggering boy’.”

Mrs. Taha: “At the start of every educational year, Mohsen had to encounter the same problems in order to interact with the others at the school. Usually, it took several months for the students and teachers to know Mohsen and to get convinced that he was a smart boy with high potential to get brilliant grades, although his special needs were not fully met. For example, one of Mohsen’s problems was with the spelling exam in which his performance was so slow. Mohsen’s handwriting was also so illegible that teachers could not read to grade. Given the absence of an educational assistant for a student with that kind of disability, I had to accompany my son to his classes, to reiterate the teacher’s spelling words for him and to translate Mohsen’s scribbles for his teachers. Sometimes, I even begged Mohsen’s teachers to allocate him more time so that he could finish his answer sheet. Whenever Mohsen could receive his special support, he would make the highest scores among his classmates.”

“I was not only my son’s educational assistant in his classes, but also his only pal at the school, ‘cause most of the students were reluctant to befriend him. Making fun of him for his physical differences, there were also boys who never stopped bullying Mohsen. Even a gang of unruly boys had named my son ‘Michael Jackson’ for his ‘dance-like movements’... Very heart-wrenching for a mom to witness all of those harsh behaviors that a society can show to her defenseless child (Mrs. Taha starts weeping)... In such a merciless environment, my son needed

to be guarded by someone, and I was there for him. I have to mention that there were also few boys at school kind enough to take Mohsen's hand to the class and to smile at him. They liked Mohsen and helped him sometimes, but were too young to endure Mohsen's slowness."

"On the other hand, since Mohsen had rejected using a wheelchair, I was so worried about his daily journey to school that I used to accompany him on most days. On the way to school, we could hear some people mumbling, 'why do you take this cripple kid to school? Let him stay at home! Do not suffer yourself for such a handicapped child! Does he need to go to school at all? Just take him to an institution and leave him there!' For all of us in the family, such merciless comments were more heartbreaking than Mohsen's physical disability. They thought that Mohsen was intellectually disabled and could not understand anything. Even if he was intellectually disabled, his dignity as a human being should not be spoiled like that."

Mr. Taha: "For several years, we possessed no home and had to move to new places every other year. Changing locations did affect the whole family. We had to restart adjusting with the new environment and the new neighbors who had got the same traditional attitude towards disability. For example, before starting of a new academic year, I found another regular school nearby our house to register my son. After talking to the school principal and showing him Mohsen's brilliant grades in the previous regular schools, the principal decided to admit such a student with physical disability. Since Mohsen was not present at the registration day, the principal had no idea about the extent of his disability."

"The first day that Mohsen arrived at school, the guard blocked his way, shouting, 'Get out of here! No beggars at school!' Mohsen tried to explain that he was also a student, but the man pulled his sleeve and kicked him off the school property. The next day, Mohsen and I went straight to the principal's office. He was surprised by seeing Mohsen and said if he had known that Mohsen was 'so disabled like that', he would never have admitted him!"

"Year after year, we had to encounter the same social problems. I think Mohsen is the only Iranian person with severe cerebral palsy who has been able to enter and endure the regular schools from 1988, when the idea of educational inclusion has not even been suggested in Iran. Mohsen finished high school successfully and got his diploma while many people, even the educated ones, still believed that he had to study in special schools rather than the regular one."

Mahbubeh: "My brother has been gifted with special abilities, such as writing stories and poems. When he was a 7th grade student, he asked a handful of the nice boys at his school to help him to write down his creative writings. He named his small group as 'The Futurists'. I also used to re-write his scribbling notes from the day that he learned how to write. I enjoyed his poems and stories, and was sure that he would have a bright future if he would follow his talent, and if the society would let him show himself."

Mr. Taha: "In Iran, it is literally difficult to enter university after high school. The applicants must pass a very difficult exam in which only 25 percent of 2 million students will be admitted. Mohsen successfully passed that exam and was admitted in Persian Language and Literature at Allame Tabatabaee University, which is one the best public schools in the country. The first day that he entered the school, the guard shouted, 'Hey boy, where are you going? Get

out of here!’ Mohsen had a very hard time to convince that man. You see... repeating stories at every single step of improvement.”

“All these have happened to my family since 1981. Over those decades, the society was not as informed as today, and disability NGOs had not started working on disability rights yet. We had to fight with a society that knew nothing about the rights of individuals with disability. Though we have been supporting Mohsen from different aspects, he has done his best to be able to stand on his own feet. There exist cultural difficulties, especially in a traditional society like Iran. I think Iranian families who have one or more members with disabilities encounter the problems that have been already solved in the developed countries, because in those countries disability rights have been systematically formulated and require the least intervention by families. Families with a disabled child in a developing country like Iran suffer too much, ‘cause they must carry the load that should be borne by a regular system of disability rights. For example, The *Comprehensive Law to Protect Disability Rights* that was enacted in 2004 by the Iran Islamic Parliament has no ‘implication guarantee’ yet [consequence for violations]; and therefore, could not fully remove discrimination based on disability. Consequently, the families still have to compensate for the legislative and administrative inefficiency.

Mrs. Taha: “We have gone through difficulties for more than 30 years... Sometimes, we have thought that God has had certain reasons for creating Mohsen like this, and therefore, we must admit it with open hearts. We have practiced thinking positively, to focus on Mohsen’s abilities, to wash off the negative feelings that an ignorant uninformed society has presented us constantly... We have tried to treat Mohsen’s disability much differently than the traditional attitude... My husband and I, now, feel exhausted from life-long fighting with society... They made us sick... We are both under medication, not because of our son’s disability, but because of what people have done to us intentionally or unintentionally Of course, we have also had understanding companions in our long journey: some of our friends, our relatives, Mohsen’s teachers... They have always been with us... They encouraged us not to give up, and we thank them all.”

The Nature and Source of Family Reaction to Disability

Jaeger and Bowman (2005) listed social reactions to disability as marginalizing, ignoring, stereotyping, misidentification, and discomfort, common reactions which occur frequently in Iranian society as well. Persons with disabilities in Iran suffer from being traditionally ignored, undermined, misunderstood, marginalized, and pitied. Most family narratives of disability in developing societies such as Iran signify that the moral, medical and religious perspectives of disability are vehemently prevalent. Moral models outline disability as a shame to both disabled individuals and their families (Goodley, 2011). Accordingly, traditional perceptions of disability in Iranian society force most of the families, especially in the small towns, to hide their disabled member(s) at homes to shield the embarrassment.

The medical model is also a prevalent approach to disability in Iran, delineating disability as a problem located within the body or mind of individuals that should be fixed (Goodley, 2011). From this point of view, Mohsen has a physical and/or mental problem that needs to be healed either by professionals or through miracles. Jaeger and Bowman (2005) referred to the

significant role of religious beliefs, such as miracles, in the public perception and attitudes toward persons with disabilities. Therefore, in addition to moral and medical perspectives, a religious point of view is also common, inviting the true believers to show pity to the poor and disabled members of the community. In fact, following the “miracle” perspective, it seems that the “charity” point of view is a prevalent social reaction to disability in Iran. Hence, Mohsen and his family frequently encounter people in the streets who wish to “help” Mohsen by putting coins in his hand.

Numerous Iranian families with a disabled member argue that they suffer not only from witnessing how their loved one has to encounter the social ignorance, insult, denial, and segregation, but also from feeling deeply humiliated by the mainstream for having a disability in the family (Hosseini, 2008). Ferguson (2001) described the significance of social context in shaping personal reactions, as well as the “nature” and the “source” of family response to disability. According to a number of Iranian family narratives (Hosseini, 2008), the nature of their reaction to the disability of their loved one consists of different feelings of grief, failure, “shame” and “depression” that Browns (2001) referred to as the negative attitudes of families toward disability. Although there is no official record of the number of Iranian families who prefer to “hide” (Ingstad, 2001) their children/members with disabilities, some stories on mistreating disabled members in and out of their families are often released by the media.

Mohsen’s family members have delineated their difficulties over 30 years. Like many parents facing the reality of disability, Mr. and Mrs. Taha have gone through different stages; from anger to acceptance, from absolute disappointment to expecting the promise of a new day; contrary feelings that Ingstad (2001) referred to as “problem” and “hope” for disabled individuals and their families in developing countries.

During the first years of discovering Mohsen’s disability, his parents could hardly admit it. Instead they were expecting a “miracle” to happen and “cure” their son. Awaiting a miracle to happen is a common reaction among persons with disability and their families in Iran. It is actually a religious term that lies primarily in Islamic beliefs. Most of the Muslims believe that miracles are likely to happen in the lives of the true believers, especially at times of distress. In the Quran, there are stories of Prophet Jesus’ miracles in healing blind people and reviving the dead (The Quran: The House of ‘Imran: 49). This religious perspective seems to act as a contextual source (Ferguson, 2001) of individuals’ and families’ reactions to disability.

The Tahas have also been living with a permanent stress not only because having a member with disability is a stressful event (Ferguson, 2001), but also mainly because of the negative reactions of the mainstream, the lack of social information about disabilities, and the absence of environmental facilities that accelerate the social participation of disabled people. Imagine parents who have to let their son with severe cerebral palsy to go to school by himself. Their stress increases as the son puts the first step out of the house, because of sidewalks full of humps, busy streets with no pedestrian bridges, ignorant citizens, and some ill-willed persons’ intentions to abuse a disabled boy.

There is seemingly a meaningful relationship between environmental facilities and the extent of stress experienced by individuals with disability and their families. Fatemeh Bozorgnia

(1938-2002), an Iranian disability advocate who lived with the after-effects of Polio for more than six decades, referred to her “better feelings” of “less fear” and “less stress” while residing temporarily in the United States in comparison with her disability experience in Iran. She claimed that the social environment in a developed country like the States has been so increasingly accessible for persons with disabilities that they feel more comfortable and less stressed than those in less accessible countries (Bozorgnia, 2011). She also indicated that even her family could benefit indirectly from those facilities, since there was no need to accompany their disabled relative in a well-equipped safe environment. Actually, most of Iranian individuals with disabilities believe that adequate environmental facilities will increase the feelings of independence, dignity, protection, safeness, and security in both the person and their families (Hosseini, 2008).

There are few Iranian families who, like the Tahas, go beyond the mainstream stereotypes and clichés in reaction to the disability of their relatives (Hosseini, 2008). In other words, Mohsen’s family represents a small number of Iranian middle-class families who, despite hindering social reactions, have been able to shape their own response to disability. According to the social model of disability (Altman, 2001), social barriers reduce opportunities to take part in social life; however, the Tahas refused to let limited societal facilities impede Mohsen’s communal activities.

Neely-Barnes and Graff (2001) referred to a handful of inquiries on the consequences of being the sibling of a person with disability. They noted that those studies have found both negative and positive impacts like wrath, unhappiness, jealousy, as well as family intimacy and personal improvement. Mahbubeh emphasized that Mohsen’s disability brought unity to the family. Although the disability of a child is reported numerous times as one of the main reasons for divorces and collapse of families in Iran, as mentioned earlier, it is likely that disability also increases closeness and intimacy in families, like the Tahas, who have had strong bonds (Havens, 2005). On the other hand, sibling jealousy of the child with a disability who is viewed as receiving more parental services (Havens, 2005) has not apparently happened in the Taha family, according to Mohsen’s sister, who instead has voluntarily helped her parents to improve Mohsen’s life.

Patterns to Adapt to the Stress

Ferguson (2001) has referred to the possibility of adaptation to stress within the disabled individual and their families. It seems that some Iranians have found certain patterns to adapt to the stress, as well as to their other negative feelings. According to the narratives of a number of Iranian persons with physical disabilities and their families (Hosseini, 2008), religious beliefs have assisted them in harnessing the anger and stress of having a child with a disability. Linguistically, “Islam” means “submission to God’s will without any objection,” and a true Muslim must practice that kind of absolute obedience in every aspect of her/his life. In addition, according to Islamic beliefs, there are undiscovered and unknown reasons for any mundane event that only God is aware of. A Muslim who trusts God truly, never questions Him for the reasons. Disability is an event that could happen in anybody’s life for a reason, and a true believer should not only submit to God’s will for creating an individual with disability, but also should not inquire of Him about the reasons. This attitude seems to assist in the positive acceptance of the

reality of disability, and to cope with the negative consequences of what Ferguson (2001) called “internal and external influences.”

Besides the religious attitude toward disability, “positivity” seems to be another pattern to adapt to stress in the Taha Family, as well as in a number of other Iranians with disabilities and their families. As they described, the Tahas have practiced focusing on Mohsen’s abilities, defining his personality by his individuality rather than his disabled body, and teaching Mohsen to see himself as perfect as a non-disabled individual. Mohsen’s parents found out, eventually, that changing their own minds was much easier than changing a context as big as a society.

Finally, they talked about the role of close friends and relatives in improving their strength. Though the number of understanding persons is not too big in comparison with the number of mainstream people, even that small number seems so effective. Those people, like a compassionate teacher, a sympathetic friend, and a friendly neighbor, have been encouraging Mohsen and his family to pursue their goals diligently.

Practicing the Academic Concepts of Disability

Since the pillars of disability studies are built upon Anglo-Saxon culture and history, this field of study is almost unknown in some developing countries like Iran. However, a number of concepts and theories of this academic field are permanently practiced by disabled individuals and their families in developing societies. For instance, confronting the mainstream reactions to disability, both disabled individuals and their families, such as the Tahas, are consistently encountering the “moral” and “medical” attitudes towards disability; and by practicing how to adjust positively to those traditional reactions, they seem constantly to be responding in accordance with the “social” model.

Permanent practicing of at least three models of disability in the daily lives of disabled individuals and their families, such as the Tahas, suggests that some of the concepts and theories of Western disability studies are applicable within non-Western contexts. In other words, the individual and family narratives of disability from different geographical origins seem to share common spotlights, as Ingstad (2001) documented similar disability reports from developing countries. For instance, most of the Taha family friends and neighbors believed that Mohsen’s parents should not take their “handicapped” son to school and had to keep (imprison) him in the house or in an institution (moral and medical attitudes). Yet Mr. and Mrs. Taha refused to play the traditional role of ashamed parents. Rather, by taking Mohsen to a regular school and exposing him to the eyes of the public, they tried to advance the goals of the disability rights movement, i.e. the right to get out of the house, and to eliminate the social barriers preventing their son from participating fully in society (social model).

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(in Farsi language) to introduce Disability Studies to her native country, where, as she claims, there is little awareness on this growing subject.

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