


Redefining Disability in Iran through Entertainment Education

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Abstract

Inclusion begins with awareness. In my country, Iran, the social attitudes and perspectives about disability are very different from those in western countries. I became aware of this when I stepped out of my country and spent the past five years in Malaysia and Canada in pursuit of graphic design education. In Canada, I learned about inclusive design, disability rights and disability culture; I experienced a more inclusive society. I wanted to create awareness among Iranians about the disability situation in Iran to initiate a socio-cultural change in my country. Adopting an artistic approach, I employed entertainment education tools to create a documentary video about the status of children with Down syndrome in Iran. By making it available on the Internet to Iranians in and outside of Iran, as well as to the rest of the world, I hope to help raise public awareness about disability to create conditions that could lead to a more inclusive society.

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I thank my family, without whose encouragement all this would not have been possible.

Finally, but most importantly, I would like to thank the children with Down syndrome, their families and the camera crew who helped in producing the documentary video and made my dream come true.

¹ Scott Page in *The Difference: How the Power of Diversity Creates Better Groups, Firms, Schools, and Societies* (Princeton, 2007).

Dedication

To my parents.

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1 **Background**

In their paper on artistic exploration of disability in Iran, Verstraete and Goethem (2012, p.81), express the paucity of studies relating to disability in Iran as follows:

There is a lack of studies examining the meanings attributed to disability in Eastern contexts. This is especially true in the case of the Islamic Republic of Iran. Studies – accessible for non-Farsi readers – dealing with the existence and position of persons with disabilities in contemporary Iran are rare.

Addressing this gap, I intend to provide an artistic glimpse of life with disability in Iran through my Major Research Project. The goal of the project is to raise public awareness in Iran about different disabilities, dispel misconceptions and create communities and cultures that support people with disabilities. Thereby, I hope to create conditions that support public dialogues around how disability should be approached, effectively leading to a redefinition of disability in Iran. To achieve the above objective, I chose an artistic approach, similar to some contemporary Iranian painters, photographers and film directors in whose works “the bodily reality of disability [is] transformed into a meaningful, effective and efficient metaphorical instrument” to stimulate public debates (Verstraete & Goethem, 2012, p.84). Through the production of a series of Web TV programs around disability, I intend to leverage the mass educational impact of entertainment through new media (Singhal, 2004) to achieve my objective. This report

describes and discusses the first program in this series, which is about living with Down syndrome, an intellectual disability.

1.1 Iranian Perspectives on Disability

The Islamic Republic of Iran is a large country in the Middle East, with a history of over 5000 years. A population that is 99% muslim, with diverse ethnic groups having their own specific values and beliefs, makes Iranian culture unique and different from that of most of the western countries (Kashani-Sabet, 2010).

About 3 million Iranians (4% of the country's total population of 70 million) have some form of disability, one of the reasons for this number being the Iran-Iraq War of 1980-88 (Adib-sereshki & Salenhpour, 2011). The Iranian Rehabilitation Society and the National Society for the Protection of Children, both founded in the 1960s, have inspired the creation of nearly 250 disability-related Non Governmental Organizations throughout the country. Despite their efforts, the needs of the disabled population are not well recognized either by the society or by the government (Salenhpour & Adib-sereshki, 2001).

Although laws have been formulated about the rights of people with disabilities, a mechanism to ensure that they are implemented is absent (Moore & Kornblet, 2011). For example, while the law requires public buildings to be fully accessible, in practice, little progress has been made

(Bahreini, 2007). Similarly, most public transportation is not accessible to the majority of persons with disabilities.

In his report on the *Status of Intellectual Disabilities in the Islamic Republic of Iran*, Samadi (2008) has recorded that about 25% of the country's population at that time was under 15 years of age, of whom around 360,000 children had intellectual disabilities. The Iranian Special Education Organization (ISEO), however, had a record of just 1.3% of these. No statistics are available for adults with such disabilities (Rassafiani & Zeinali, 2007). Down syndrome is one such disability, which is more common in Iran due to prevalence of consanguineous (inter-cousin) marriages (Mokhtari & Bagga, 2003). Education, for these children, is a rare privilege.

In the Iranian society, considerable stigma is attached to the presence of a family member with intellectual disability. In the new constitution in Iran, the word "Mahjor," which means "Lunatic and Immature," and had a traditionally negative connotation, has been chosen to describe persons with intellectual disabilities (Samadi, 2008). The Iranian government is reluctant to acknowledge disability as a social issue rather than a social stigma, and to take measures to manage it (Samadi, 2008). On the other hand, parents are working on establishing organizations and advocating for the rights of individuals with disabilities. A well-known example is the Iranian Association of Down Syndrome. Although there are some associations and initiatives

promoting self-advocacy of persons with disabilities, there is a continued need to strengthen these and to embrace all people with disabilities.

1.2 Problem Statement

I have always felt a natural sense of social responsibility towards my country, Iran. I would participate in street protests in Iran to uphold our human rights in the context of political problems. I left Iran five years ago to continue my education as a graphic designer, living three years in Malaysia and two years in Canada. Life in these two countries gave me different, new perspectives of how culture and society are connected. Learning about Inclusive Design in Canada opened up in me new thoughts about an inclusive society in my country. While I saw my classmates and other people in Canada do their best to make the country more accessible for people with disabilities, I realized how little we, in Iran, pay attention to disability. I wondered whether a possible reason for this difference between Canada and Iran could be a lower level of awareness, information and education about disability in the country, and whether enhancing awareness about disability in Iran through mass education might reduce this difference.

1.3 Design Approach

My background in art prompted me to extend my above personal journey into an artistic journey and portray the lived experiences of people with disabilities in Iran as a vehicle for public engagement and debate. By

extending my personal exploration artistically, I sought to create a means for the (Iranian) public to join me in that part of my journey that challenged the definitions of disability in Iran (when compared to other definitions in places like Canada.) By allowing the public to go into my artistic exploration, I hoped to be able to use the artistic process to gain a greater understanding, bringing the public along in the process. I decided to make documentary videos around disability in Iran with the objective of creating socio-cultural awareness about the topic.

A change in social cultures could happen through inspiring people to respect others' beliefs also and not just their own. Issues that are sensitive and therefore not discussed must be taken to the people to promote dialogue and awareness. An effective approach for this is provided by critical pedagogy, which is "an educational movement, guided by passion and principle, to help [learners] develop consciousness of freedom, recognize authoritarian tendencies, and connect knowledge to power and the ability to take constructive action" (Giroux, 2010, p.1). This anti-authoritarian and interactive approach questions oppressive social controls and empowers the learners.

Singhal (2004) suggests that education of the masses is best achieved through entertainment. Informing people about current cultural problems and ways for solving them could therefore be done through making a

documentary as an entertainment media. Entertainment education (discussed in greater detail in Section 2) involves the designing and implementing of a media message to entertain as well as to educate the audience about an issue, create favorable attitudes, and change overt behavior (Singhal, 2004). It uses the appeal of popular media to show people how they can live better.

I planned a Web TV series around the topic of disability in Iran where documentary videos will be hosted on the Internet so that the messages reach the masses in Iran without much filtering by the government. The goal of the project is to bring about socio-cultural awareness about the need to make life easier for people with disabilities in Iran, thereby motivating the Persian society to work towards higher, common goals and to make the country a better place for everyone to live in.

As the first program in the series, I produced a documentary video on the lives of children with Down syndrome in Iran. Theoretical implications of this approach are examined in Section 2 of this report. The video production process is described in Section 3 and the anticipated effects on viewers are discussed in Section 4. The report concludes with a review, in Section 5, of contributions made and future work anticipated.

2 **Effecting Change through Entertainment Education**

This section begins with an examination of how disability is defined in Iran and in other countries, including an auto-ethnographic account of my role as a seeker. The efficacy of entertainment education in achieving the purpose of this project is then elaborated upon, followed by an account of the artistic exploration that this project entailed. The positive role played by new media in bringing Iranians across the globe together and in providing a platform for the exchange of ideas is then highlighted, indicating thereby the suitability of artistic expression as a vehicle to achieve the project goal.

2.1 Defining Disability

The majority of studies on disability published so far focuses primarily on Western societies. According to Verstraete & Goethem, "Eastern perspectives on disability-related issues still remain largely unwritten and/or inaccessible for English-speaking scholars" (2012, p.84). While not a comprehensive overview of the topic, this section provides a brief examination of the definitions of disability in Iran in comparison with its Western counterparts.

As Linton (1998, p.9) contends, "The disability community has attempted to wrest control of the language from the previous owners, and reassign meaning to the terminology used to describe disability and disabled peoples." Culture and/or geographic location, as well as history could influence the definitions of disability. And of course, definitions are influenced by other

factors, such as religion, the political climate of a region, and so on. Disability, therefore, could be defined in numerous ways.

The definitions of disability in Iran are not in line with international definitions. The International Classification of Functioning (ICF) defines disability as an umbrella term for impairments, activity limitations, and participation restrictions. Disability here refers to the negative aspects of the interaction between individuals with a health condition (such as cerebral palsy, Down syndrome, depression) and personal and environmental factors (such as negative attitudes, inaccessible transportation and public buildings, and limited social supports).

On the other hand, the State Welfare Organization (SWO), the arm of the government in Iran that provides welfare benefits to those who qualify, defines five types of disabilities: physical, hearing, visual, mental and *janbaz* (Alaedini, 2004). *Janbaz*, which means *those who are willing to lose their lives*, refers to people who became disabled during the Iran-Iraq War. These definitions are not comprehensive, in that they prove inadequate for comparing disability data from Iran with that from other countries. For example, the World Health Organization (2011) estimates disability in America as around 13 to 16 percent, while the Iran government estimates about four percent of its population to be disabled.

The Disability Protection Act of 2003 defines a disabled person as one whose physical or mental impairment substantially prevents him from participating in one or more major life activities (Iranian Society of Disabled Persons, 2004). As such, this interpretation “disregards the social arrangements that are the cause of the so-called ‘restricted activity’ of the disabled, and fails to recognize the discriminatory barriers of the environment that prevent disabled people from functioning independently” (Bahreini, 2007, p.27).

In her historical analysis of Iranian experiences with disability, Kashani-Sabet (2010) observes as follows:

The Iranian society virtually ignored the reality of disability in the public sphere. With this omission, it failed to contend with the ways in which disability defined modern culture and influenced social life. The absence of historical information on the disabled community as a social category indicates that persons with special needs did not really constitute a recognizable class with social privileges until well into the twentieth century.

This is quite in contrast to my experience when I came to Canada to study Inclusive design. My first interesting observation was how the people and the government here paid attention to disability and how they were trying to make their country more accessible. I saw my classmates talking and thinking about problems of access and inclusion that I had never been aware of. I came to understand that, although the government of a country has an undeniable role in the development of the disability culture prevalent in the society, the society itself also helps the government in promoting this culture.

Accepting disability has to come first from the family itself. If they do not accept their child's disability, the society will also not accept it. When it comes to certain kinds of disabilities defined by society such as sexual orientation or gender issues, the society plays the same role as the family. The best way of knowing about how a particular disability is defined is by going to that group of people and asking them to introduce themselves and their abilities. The lack of connection between the people of a country and particular groups in society may cause much misunderstanding. If the family accepts disability, the society will; if the society does, then the government will be forced to do so. Promotion of awareness, therefore, has to be targeted at the grass roots in the form of mass education. How entertainment offers a potential medium for mass education is examined in the next sub-section.

2.2 Education through Entertainment

Entertainment is considered one of the most pervasive genres of mass media; it spreads ideas that shape how people dress, speak, think, and behave (Piotrow, 1990). It is usually thought that mass media programs must either be entertaining or educational. Education happens through entertainment media, even if unintended by the source and unnoticed by the audience (Singhal & Rogers, 2012).

What I refer to in this document, as 'Entertainment Education' is not a new phenomenon. It has been around for centuries in the form of theater, books,

and storytelling. But the emergence of mass media, such as television, Internet, radio, and mobile phones, has transformed entertainment education. *Sesame Street*, an educational program for preschoolers, is an exceptional example of successful Entertainment Education.

Technological advances make Entertainment Education a sustainable, quick and cost-effective way to provide information and education to very large numbers of people - literally in the billions.¹ The CDC (Centers for Disease Control and Prevention) has an Entertainment Education program for promoting health awareness and education through mass media.²

Singhal and Rogers define Entertainment Education as follows: "It is the process of purposely designing and implementing a media message to both entertain and educate in order to increase audience members' knowledge about an educational issue, create favorable attitude, shift social norms, and change the overt behavior of individuals and communities" (1999. p.9). Entertainment Education is not a communication theory but a "communication strategy" intended to create a positive change among intended audiences (Singhal & Rogers, 2004. p.5). How this strategy was used in the production of the art piece (documentary video) is described in the next section.

¹ <http://wbi.worldbank.org/wbi/content/entertainment-education-0>

² www.cdc.gov/healthcommunication/ToolsTemplates/EntertainmentEd/

2.3 Artistic Exploration

Verstraete and Goethem, in their report on artistic exploration of disability in Iran, state that symbolic representations of disability enables artists to express their particular worldviews and give voice to their creative insights (2012, p.81). I decided that artistic exploration would, therefore, be an appropriate approach for my project, and entertainment education would be a useful tool to achieve its goal.

Art-based research can be defined as the systematic use of the artistic process, the actual making of artistic expressions in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies. These inquiries are distinguished from research activities where the arts may play a significant role but are essentially used as data for investigations that take place within academic disciplines that utilize more traditional scientific, verbal, and mathematic descriptions and analyses of phenomena (Knowles & Cole, 2008).

Both art-based research and science involve the use of systematic experimentation with the goal of gaining knowledge about life. Where science focuses on what can be objectively measured, art emphasizes the unique and immeasurable aesthetic qualities of a particular work. As W. E. Beveridge (1953) describes in *The Art of Scientific Investigation*, original knowledge

occurs when ideas are placed in new relationships to one another, a process that typically requires crossing the boundaries of previously separated domains, such as those constructed between art and science (Knowles & Cole, 2008). New media offers today a rich domain for artistic exploration and a broad medium for reaching out to audiences. The positioning of new media within the Iranian context is discussed below.

2.4 New Media and Socio-cultural Changes in Iran

The Internet was introduced in Iran in 1993 and has experienced exponential growth since then. From 2001 to 2009 Internet usage increased annually by 48 percent (OpenNet Initiative, 2009). As of June 2012, there were around 42 million Internet users in Iran amounting to 53.3 percent of the population (Internet world stats, 2012). However, only a small fraction of these users have access to high speed Internet. Iran is also one of the leading Internet filterers in the world, primarily for political purposes (OpenNet Initiative, 2009). Millions in Iran view satellite channels based in the US and Europe. These channels have a socio-cultural impact (Sohrabi-Haghighat, 2011.)

New media has helped bridge the deep gap that existed between activists inside and outside Iran. Iranians around the world come together online for the latest news coverage as well as to exchange ideas, notwithstanding stringent measures taken by the government (Sohrabi-Haghighat, 2011.) By

hosting videos on the Internet, I will be able to create a direct impact on Iranians in and outside of Iran.

The word "culture" has been used in Persian literature with various concepts such as knowledge, science and wisdom (Salehi & Mohammadi, 2010). Customs, beliefs, value systems and social norms are some aspects of culture (Ghaysvandi, Mostafaei & Mostafaei, 2013). Social change is the process by which an alteration occurs in the structure and function of a social system. Social change is a collective phenomenon and includes the society or an important part of the society. Wilbert Moore defines social change as changes in behavioral patterns and culture of a society that include norms and values (Ghafari & Ebrahimi, 2010). Social and cultural changes are caused by human sources (Salehi & Mohammadi, 2010). New media effectively connects human sources to effect and spread these changes.

The goal of this project is to initiate a process of socio-cultural awareness around disability in Iran through the medium of entertainment education using new media. The next section describes how a documentary video on children with Down syndrome in Iran was produced as a first step towards achieving this goal.

3 The Production Process

In my opinion, one of the important factors behind the Iranian society being less inclusive and accessible with respect to disability is the manner in which people approach other people with impairments and the resulting culture of disability in Iran. When people feel for and express the need for an accessible society the government will be forced to answer to the need. Therefore, to connect people to the term disability in a renewed way, I decided to make a documentary video portraying the lives of families living with children with Down syndrome and organizations supporting them.

To begin with, it was important for myself to find out what disability really means. While trying to understand this, I read through several books about the definition(s) of disability in Iran and in other countries. After knowing what disability means, the first thing that came to my mind was that I have never seen any disabled children in Iran. I realized that this could be because the government and the society never thought in terms of making Iran accessible for people with impairments. I decided to go to the people with disabilities to hear what they really think about the culture of disability in Iran. So the social awareness resulting from my video would be in their own people who had physical and mental impairments and view their world through their eyes. [[disability in Iran and my target audience being

Iranians, I went to my country from December 2013 to March 2014 and worked on my project there.

First, I went to the Iran University of Social Welfare and Rehabilitation Sciences and met Dr Mehdi Rassafiani, Associate professor in the department of Occupational Therapy. He introduced me to Dr. Mojgan Hemati whose son has Down syndrome. After talking to her I decided to choose Down syndrome as the theme for the documentary. Dr. Hemati referred me to the Iranian Down Syndrome Institute. Before walking into the institute I was filled with many doubts about how should I talk to the children and behave with them. Although I do not believe in the word disability, I was very stressed about how they would react.

I attended their classes, and got introduced to three families who had children with Down syndrome. I spoke with them, went to their personal classes for about a month and gathered information about their problems and needs. They behaved very nicely with me. After a few days, I found that they really are not any different from me and some of them even have a lot more than me to show by way of achievements.

Thereafter, I made a documentary video, whose purpose is to inform the society about what disability really means. During this artistic exploration I got to look at the gold medals won at the World Special Olympics by one of the persons who participated in the documentary. That achievement amazed

me and brought me to the conclusion that disability does not exist in anyone exclusively. We are all bundles of a variety of abilities and disabilities.

Among the children with Down syndrome that I met at the Institute, I chose three boys aged four, six and 24. Their parents eagerly wanted to be part of the video because they told me that no one here cares much about their needs and my movie would be an effective way for them to communicate to the people and the government. So they helped me a lot in making the video.

Taha Namazi is a four-year-old boy who was really good at talking and he was one of the best in occupational therapy. His independence in doing his own personal work attracted my attention. Also, his mother was very confident and positive about him. The main problem with these children is that their parents usually have some psychological reservations in accepting the children, I found Taha's mother to be a good example of how strong a mother can be and how she could educate her child.



Figure 1 Taha Namazi

The second child is Farzad Moradi, who was introduced to me by the founder of the Down Syndrome Institute. He is six years old. He is so smart and sociable that they believed he could go to a regular school and does not require special education. Some parents avoid enrolling their children in regular schools fearing how other children might behave towards their children. For this reason Farzad's parents preferred that he be educated in a healthier environment.



Figure 2 Farzad Moradi

The third person that I chose for the documentary is 24-year-old Mohammad Tajadod. He is the winner of two gold medals for swimming in World Special Olympics and one silver medal for jogging on the ice in the USA.



Figure 3 Mohammad Tajadod

Mohammad is from one of the well-known families in Tehran. His parents are well educated. They raised him with plenty of training in swimming, futsal (running), art and computer usage. The most interesting thing I found about Mohammad is that he is only one year younger to me and yet so much more accomplished.

I decide to show a day in their lives through conversations with the parents of the above three chosen persons with Down syndrome interspersed with an

interview with Ms. Poorandokht Bonyadi, founder of the Iranian Down Syndrome Institute.



Figure 4 Ms. Bonyadi, Director, Down Syndrome Institute, Tehran

As the producer of the video, I obtained release forms (as displayed in Appendix A) from or on behalf of each of the participants in the video listed below:

- Taha Namazi - Four-year old boy with Down syndrome
- Farzad – Six-year old boy with Down syndrome
- Mr. Moradi - Farzad’s father

- Mrs. Moradi - Farzad's mother
- Mohammad – 24-year old person with Down syndrome
- Mr. Tajadod – Mohammad's father
- Mrs. Tajadod – Mohammad's mother
- Ms. Poorandokht Bonyadi, Director, Down Syndrome Institute
- Mr. Haji Zadeh, Down syndrome child psychologist

The documentary was shot at the Iranian Down Syndrome Institute as well as the residences of the three families that participated.



Figure 5 Setting the scene

The video starts with sound effects and psychedelic animations in red color to portray suspense about what is to come. The colourful animations lasting for over a minute also provide a sense of unknown emotions that children with Down syndrome might be going through. Scene 1 starts with a conversation with Farzad's parents about whether they knew what Down syndrome was before Farhad was born.



Figure 6 Farzad, the relentless painter

Scene 2 unfolds with a boy with Down syndrome (Farhad) painting on a wall with broad brush strokes of bright red colour. Music plays, and titles are

displayed. The boy is wearing thick eye-glasses and a full sleeve top of red and black colour. His total attention is on the painting task. He sometimes uses his finger, and sometimes the brush. After finishing with red, he uses black paint, and then green. He paints squares, circles and triangles, filling the spaces with colour. Finally a still photograph shows him in the backdrop of his paintings, facing the audience with his hands held up in a mood of jubilation and accomplishment. The music slows in tempo and stops.

The documentary continues with an introduction to Down syndrome by Ms. Bonyadi of the Down Syndrome Institute and the problems these children have in their life. Ms. Bonyadi told us that the birth of her daughter Ayda with Down syndrome prompted her to research about the condition and eventually establish the Institute. The institute accepts children with Down syndrome from the age of 30 days till much older ages. Classes are conducted on several topics such as occupational therapy, speech-language pathology, art and music. The Institute played a big role in recognizing Mohammad's abilities and preparing him for participating in the World Special Olympics. Figure 7 shows Mohammad talking about his participating in the Olympics and winning medals.



Figure 7 Mohammad with his medals

Further scenes in the documentary revolve around conversations with the three families to bring out their struggles, emotions and lessons learned. My main objective is to encourage and inspire parents that have a child with Down syndrome by showing how the parents of these three children have supported and educated them, thus helping them to use their abilities.

This section described the process of producing the documentary video for the project. The next section provides my personal reflections on the outcomes of the project.

4 **Personal Reflections**

Change, like charity, begins at home. The process of making a documentary video around the lives of children with Down syndrome changed my own perspective about disability. I understood that life with a disability entails multi-dimensional problems. During my conversations with parents of children having Down syndrome, in the course of producing the video, they shared with me different aspects of their lives and their problems. Some issues that beg greater attention from the government and the society are described below.

4.1 Issues Identified for Enhancing Awareness

Need for better health care facilities: Children with Down syndrome lack special medical clinics where they can go for check up periodically. The mother of one of the children told me that these children typically have weak heart, lungs, teeth and skin. They need to be checked up every month but there is not a single clinic in the city for them to go to. The father of another child told me that some of the general practitioner doctors don't care much about the health situation of children with Down syndrome, and if anything happens to them, rather than treating the children, they declare it as something normal in children. Treatments for conditions associated with Down syndrome are too expensive for families with an average income to

afford. Parents considered eye care (including eyeglasses) and dental care as the two most expensive health treatments.

Need for mental health care for parents: Another cause for concern is the mental health of the parents. Usually these parents are in a state of deep depression because they cannot accept their children's situation. It is especially evident in younger parents whose first child is diagnosed with Down syndrome. It is important for the family to maintain good mental health in order to help the children find their abilities, but unfortunately most of the family members do not visit a psychologist. In fact, after some time they avoid showing their children to the society. They told me that there are several parents who never allow photographs of their children to be taken; and some of them even end their relationship with their families to hide their child. I think, therefore, that the government should employ psychologists to support these parents and provide free counseling to them.

Need for better awareness about planning for the future: Several parents do not know about choosing a testamentary guardian³. They need to be informed that before their death they could, and should, choose a person to take care of their child with Down syndrome. Where a child does not have

³ The Merriam-Webster dictionary defines 'testamentary guardian' as a person appointed by deed or will by a father to act as guardian of his minor child. Usually testamentary guardians are appointed by a widowed parent of a minor child or disabled adult child to render assistance to the children (<http://definitions.uslegal.com/t/testamentary-guardian>. Last accessed June 4, 2014.)

a registered testamentary guardian, the law requires the child to be handed over to its grandparents after the death of the parents; and if the grandparents themselves are not fit then the child cannot take care of his life. So it is really important that the parents choose a healthy person with a reasonable income as the testamentary guardian of their child before their death. Unfortunately most of the parents with Down syndrome children do not know about this.

Need for greater sensitivity: Because of the resemblance of the eyes of Down syndrome children with 'Mongolians', Iranians commonly call someone with Down syndrome as 'Mongol'. In fact, this practice is prevalent to such an extent that when I used the term 'Down syndrome' while talking about my project, most of the people asked me who I was talking about, and I had to use the term 'Mongol' to make them understand. This term carries a very negative tone and its use in the society needs to be discouraged.

These are some of the more serious problems that need to be solved and this requires simultaneous action from the government and the society. By producing a video about Iranian children with Down syndrome, I believe I have created an Entertainment Education tool that will enhance social awareness and initiate a change in thinking in this area, as illustrated below.

4.2 Expected Impact

The effectiveness of Entertainment Education in bringing about social change has been repeatedly established. Research has shown that Entertainment Education could influence viewers. The number of calls to the National STD and AIDS Hotline dramatically increased after the daytime soap opera *The Bold & Beautiful* featured HIV prevention messages (Kennedy, O'Leary, Beck, Pollard, & Simpson, 2004). I hope that more parents become aware of facilities such as the Down Syndrome Institute and contact them for help with their children.

The most frequently employed theory to explain Entertainment Education is social cognitive theory (Bandura, 1986; 2004). According to the theory, people learn by observing others' action and its outcome, and this observational learning is motivated by outcome expectancies and self-efficacy (Bandura, 2004). Therefore, a person who observes a model whose behavior is rewarded is more likely to model that behavior. Similarly, observing an accomplishment of a model similar to a viewer can increase the viewer's self-efficacy and self-confidence to perform the behavior (Bandura, 2004). On similar lines, I am sure parents of children with Down syndrome, after watching the video, will feel motivated to maintain a positive attitude towards their children, try to provide them with opportunities to realize their true potential, and feel truly proud of them.

Papa & Singhal (2009) state that mass media messages often prompt dialogue among listeners or viewers that might lead to pro-social change. An Entertainment Education program in India, developed with the intention of promoting pro-social changes such as gender equality, family planning, etc., prompted internal dialogue (parasocial interaction) between listeners and media characters, leading to conversations about the educational content of the media program. This led to pro-social change. Papa & Singhal also state that interpersonal dialogues within families and dialogues at the group level among community members were initiated, that facilitated discussion of sensitive or taboo subjects in ways that were supportive of social stability as well as social change in family and community dynamics. I hope that the contents of the documentary spark various forms of dialogue among the audience leading to social action in Iran.

This section highlighted some issues faced by persons with Down syndrome and their families and projected some possible ways in which the documentary video produced could help enhance awareness and redefine this disability in the eyes of the government and the society.

5 **Conclusion**

5.1 Contribution

It has been five years since I left Iran, starting my personal journey as an immigrant in other countries. I carried a lot of negative thoughts about the government in my country and I assumed that every social problem we have is connected with it. I lived for three years in Malaysia and two years in Canada. Living in these two countries, which are so different from Iran, made me wonder about things we take for granted in other countries that are a rarity in Iran, such as tolerance for individual differences and promotion of inclusion.

During my early exploratory work around formulating my specific approach to my MRP, I discovered that many Iranians who had immigrated to other countries continued to maintain beliefs that were not conducive to inclusion. I had the occasion to meet several Iranians outside Iran in personal social contexts and converse with them about different subjects. Surprisingly, even though they were not bound by the rules of the Iranian government any more, they were still very much connected to beliefs they had in Iran. It was even more obvious, and ironic, in Canada, a country where Iranians come seeking freedom. I found that some Iranians living in Toronto still think that homosexuality is a disease. They cannot accept political opinions different

from their own opinion. Many of them still think that women cannot be equal to men.

My personal journey was thus punctuated with experiences that consisted of more question marks than periods, leaving me with an urge to search why disability is defined in different ways in different countries and how one could redefine disability in Iran to pave way for a more inclusive society. I realized that, in many ways, governments are reflections of a society. I realized that by raising public awareness about disability, I could create conditions that could engender changes in society, ultimately influencing public policy in the long run.

Scholarly research revealed to me that reaching out to the masses through entertainment education via new media would be more impactful than through academic papers backed by research data. My background in art prompted me to adopt an artistic approach and extend my personal journey into an artistic journey to portray the lived experiences of people with disabilities in Iran. For my project this had some advantages, such as I could use the artistic process itself to gain a deeper understanding, rather than a more didactic approach that would require doing research in advance (as might be the case in a traditional educational video.)

In this project I was looking to create awareness among Iranian people about disability, and thereby spur a socio-cultural change that would lead to greater

social sensitivity towards people with disabilities and proactive social action to make education, environment, etc. accessible to them. Therefore, I adopted an artistic approach and used entertainment education tools to create a documentary about children with Down syndrome in Iran. Before I met the children with Down syndrome I was so worried about what if they are so disabled that I cannot finish my project, but spending some time with them showed me they are no different than I am – in fact, some have much better accomplishments than I do. In a sense, I experienced the change that I sought to create.

This project made me realize that influence on culture by the government and the society are intertwined. On the one hand, the government influences disability culture in Iran, but on the other hand people are the ones who confirm it. There are numerous issues that need to be introduced to the Iranian society so that they would have enough information about them. People need to get connected and remain connected to understand that every human being has some kind of disability; so disability is not a special feature that sets apart a few people anymore. We all have plenty of abilities as well, and it would be better to recognize and focus on the abilities rather than on the disabilities.

5.2 Future Work

This documentary video is the first in a series of Web TV episodes that I am planning to produce. Impact assessment of this documentary on people living in Iran as well as those living outside of Iran could be carried out using Web analytics and other tools. Based on the results, further documentaries could be produced for the Web TV series. This series will not only serve to raise public awareness among Iranians in and outside of Iran, but also provide a window into a culture that many people outside Iran do not have access to.

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Appendix A Release Forms

Release forms from (or on behalf of) the persons featuring in the documentary are given from page 40 to 44.



[08/Feb/2014]

Release Form

Production Date(s): 9/Feb/2014 – 18/April/2014

Program Title (working title): Effecting cultural change – [*Down syndrome Children In Iran*]

Participant's Name: Poorandokht Bonyadi

Producer/Production Entity: Feriyal Hallajarani (“Producer”)

Production Location: Tehran – [*Down syndrome Institute*]

I hereby authorize the Producer to record and edit into the Program and related materials my name, likeness, image, voice and participation in and performance on film, tape or otherwise for use in the above Program or parts thereof (the “Recordings”). I agree that the Program may be edited and otherwise altered at the sole discretion of the Producer and used in whole or in part for any and all broadcasting, non-broadcasting, audio/visual, and/or exhibition purposes in any manner or media, in perpetuity, throughout the world.

The Producer may use and authorize others to use all or parts of the Recordings. The Producer, her successors and assigns shall own all right, title and interest, including copyright, in and to the Program, including the Recordings, to be used and disposed of without limitation as Producer shall in its sole discretion determine.

Signature of Person Appearing: 

Date: 8/Feb/2014

Address: Haj Rezaei Alley – Tohid Street – Unit# 21

Phone: 009821 664 26210

Email: N/A



[Date]

Release Form

Production Date(s): 9/Feb/2014 – 18/April/2014

Program Title (working title): Effecting cultural change – [*Down syndrome Children In Iran*]

Participant's Name: Haji Zadeh

Producer/Production Entity: Feriyal Hallajarani (“Producer”)

Production Location: Tehran – [*Down syndrome Institute*]

I hereby authorize the Producer to record and edit into the Program and related materials my name, likeness, image, voice and participation in and performance on film, tape or otherwise for use in the above Program or parts thereof (the “Recordings”). I agree that the Program may be edited and otherwise altered at the sole discretion of the Producer and used in whole or in part for any and all broadcasting, non-broadcasting, audio/visual, and/or exhibition purposes in any manner or media, in perpetuity, throughout the world.

The Producer may use and authorize others to use all or parts of the Recordings. The Producer, her successors and assigns shall own all right, title and interest, including copyright, in and to the Program, including the Recordings, to be used and disposed of without limitation as Producer shall in its sole discretion determine.

Signature of Person Appearing:

Date: 8/Feb/2014

Address: Haj Rezaei Alley – Tohid Street – Unit# 21

Phone: 009821 664 26210

Email: N/A



[Date]

Release Form

Production Date(s): 9/Feb/2014 – 18/April/2014

Program Title (working title): Effecting cultural change – [*Down syndrome Children In Iran*]

Participant's Name: Taha Namazi

Producer/Production Entity: Feriyal Hallajarani (“Producer”)

Production Location: Tehran - [*Mr Namazi's Home – Street – Down syndrome Institute*]

I, Hamid Namazi, for and on behalf of my son Taha Namazi, hereby authorize the Producer to record and edit into the Program and related materials his name, likeness, image, voice and participation in and performance on film, tape or otherwise for use in the above Program or parts thereof (the “Recordings”). I agree that the Program may be edited and otherwise altered at the sole discretion of the Producer and used in whole or in part for any and all broadcasting, non-broadcasting, audio/visual, and/or exhibition purposes in any manner or media, in perpetuity, throughout the world.

The Producer may use and authorize others to use all or parts of the Recordings. The Producer, her successors and assigns shall own all right, title and interest, including copyright, in and to the Program, including the Recordings, to be used and disposed of without limitation as Producer shall in its sole discretion determine.

Signature of Parent of person Appearing:

Date: 8/Feb/2014

Address: Abbasi Alley – Tavakoli Street – Mehr abad – Unit# 62

Phone: 009821 666 91688

Email: N/A



[Date]

Release Form

Production Date(s): 9/Feb/2014 – 18/April/2014

Program Title (working title): Effecting cultural change – [*Down syndrome Children In Iran*]

Participant's Name: Mr. Moradi, Mrs. Moradi, Farzad Moradi

Producer/Production Entity: Feriyal Hallajarani (“Producer”)

Production Location: Tehran - [*Mr Moradi's Home – Street – Down syndrome Institute*]

I, Moradi, for and on behalf of myself, my wife and our son Farzad, hereby authorize the Producer to record and edit into the Program and related materials our name, likeness, image, voice and participation in and performance on film, tape or otherwise for use in the above Program or parts thereof (the “Recordings”). I agree that the Program may be edited and otherwise altered at the sole discretion of the Producer and used in whole or in part for any and all broadcasting, non-broadcasting, audio/visual, and/or exhibition purposes in any manner or media, in perpetuity, throughout the world.

The Producer may use and authorize others to use all or parts of the Recordings. The Producer, her successors and assigns shall own all right, title and interest, including copyright, in and to the Program, including the Recordings, to be used and disposed of without limitation as Producer shall in its sole discretion determine.

Signature of Parent of person Appearing:

Date: 8/Feb/2014

Address: Yas Alley – Chahar Baq Street – Janat Abad – Unit# 2

Phone: 009821 444 45531

Email: N/A



[Date]

Release Form

Production Date(s): 9/Feb/2014 – 18/April/2014

Program Title (working title): Effecting cultural change – [*Down syndrome Children In Iran*]

Participant's Name: Mr. Tajadod, Mrs. Tajadod, Mohammad Tajadod

Producer/Production Entity: Feriyal Hallajarani (“Producer”)

Production Location: Tehran - [*Mr Tajadod's Home – Street – Down syndrome Institute*]

I, Tajadod, for and on behalf of myself, my wife and our son Mohammad, hereby authorize the Producer to record and edit into the Program and related materials our name, likeness, image, voice and participation in and performance on film, tape or otherwise for use in the above Program or parts thereof (the “Recordings”). I agree that the Program may be edited and otherwise altered at the sole discretion of the Producer and used in whole or in part for any and all broadcasting, non-broadcasting, audio/visual, and/or exhibition purposes in any manner or media, in perpetuity, throughout the world.

The Producer may use and authorize others to use all or parts of the Recordings. The Producer, her successors and assigns shall own all right, title and interest, including copyright, in and to the Program, including the Recordings, to be used and disposed of without limitation as Producer shall in its sole discretion determine.

Signature of Parent of person Appearing:

Date: 8/Feb/2014

Address: Jalal Alley – Asef Street – Zaferaniyeh – Unit# 60

Phone: 009821 221 76410

Email: N/A

Appendix B Documentary Video Description

Characters in the video:

Feriyal Hallajarani - Producer
Taha Namazi - Four-year old boy with Down Syndrome
Farzad – Six-year old boy with Down Syndrome
Mr. Moradi - Farzad's father
Mrs. Moradi - Farzad's mother
Mohammad – 24-year old person with Down Syndrome
Mr. Tajadod – Mohammad's father
Mrs. Tajadod – Mohammad's mother
Ms. Poorandokht Bonyadi, Director, Down Syndrome Institute
Mr. Haji Zadeh, Down syndrome child psychologist

The video starts with sound effects and psychedelic animations in red color to portray suspense about what is to come. The colourful animations lasting for over a minute also provide a sense of unknown emotions that children with Down syndrome might feel.

Scene 1: [opens with Farzad's parents seated – apparently in front of someone (Feriyal) who is asking them questions; she is not seen but her voice is heard.]

Feriyal: Did you know before Farzad's birth that he had Down syndrome?

Farzad's mother: No, not before that. I mean, sonography was done but the doctors did not tell us anything.

Farzad's father: She was undergoing health checkups, but ... The children's specialist came to me and told me about that right after his birth, but we didn't tell his mom for a week.

Farzad's mother: I was suspicious because of his face.

Farzad's father: She had a doubt...

Feriyal: What was your first reaction?

Farzad's mother: I had a doubt but then I said maybe he's going to be okay; he is a new born baby, maybe that is his normal face; but I wasn't too much concerned about what the problem could be.

Feriyal: How long did it take you to know the truth, and be sure 100%?

Farzad's father: I was sure. I think I told her after a week.

Feriyal: Did you know what was Down syndrome?

Farzad's mother: No.

Scene 2: [unfolds with a boy with Down syndrome painting on a wall with broad brush strokes of bright red colour. Music plays, and titles are displayed. The boy is wearing thick eye glasses and a full sleeve top of red and black colour. His total attention is on the painting task. He sometimes uses his finger, and sometimes the brush. After finishing with red, he uses black paint, and then green. He paints squares, circles and triangles, filling the spaces with colour. Finally a still photograph shows him in the backdrop of his paintings, facing the audience with his hands held up in a mood of jubilation and accomplishment. The music slows in tempo and stops.]

Scene 3: [shows Ms. Poorandokht Bonyadi, the director of Down Syndrome Institute in Tehran, seated in her office room answering questions from Feriyal, who is invisible at this point. While Bonyadi is speaking, video clips of some children with Down syndrome at the Institute are shown to illustrate the points she makes.]

Bonyadi: Down syndrome is a genetic disorder, in fact children with Down syndrome have one more chromosome, it means instead of 46 chromosomes they have 47 chromosomes. It is typically associated with physical and mental growth delays.

Feriyal: I want to know what is this incorrect word that we use to address them; and how did the word enter our language?

Bonyadi: The word 'Mongolism' that we used before incorrectly to call this children, had been used because of the similarity of their eyes to Mongolians. But nowadays they try to call them 'persons with Down syndrome'. It is named after John Langdon Down, the British doctor who discovered this extra chromosome in these children that makes this genetic disorder. And instead of using other words, it is better to use the term 'children with Down syndrome' to refer to these children, because, unfortunately, using the word 'Mongol' brings a negative meaning socially.

Feriyal: What did you do to establish this Down Syndrome Institute? Please tell me about its history.

Bonyadi: The birth of my daughter Ayda made this happen, from the very first day, especially in her school time. I tried to create a group discussion session in school with mothers; they were really depressed. We had books to borrow, in fact we had a mobile bookstore. While Ayda was growing up, I thought that she wanted me to focus on Down syndrome. With some of the others families who had children with Down syndrome, we decided to establish this Institute.

Scene 4: [Focus returns to Farzad's parents. The camera is on their faces, capturing their emotions completely. Only Feriyal's voice is heard.]

Feriyal: How did you know that Farzad has learning ability despite of having Down syndrome?

Farzad's father: So, if we want to compare everything about Farzad with a normal child, we can say that he had one-year delay in his growth, in his crawling, walking, talking...almost he had one year delay. We lived in Isfahan. When we enquired, they told us that we can find whatever facilities we want in the welfare organization. When we went to the welfare organization, they said they don't have anything for children younger than three years old; their education starts after the age of three. Then we went to the Institute.

Feriyal: You mean the Down Syndrome Institute?

Farzad's father & mother: Yes Down syndrome institute. First they took a test. Down syndrome institute was the best place for mental education.

Scene 5: [The camera is back in Bonyadi's office to provide some more information about the Institute.]

Bonyadi: Down Syndrome Institute was established in 2003. We have a license from the Ministry of Interior and the Police. One of our first missions is the mental and physical education of people with Down syndrome and improving their personal and social life.

Scene 6: [Focus is back on Farzad's parents.]

Feriyal: What was the first word Farzad said?

Farzad's mother (emotionally and with a smile): Dad.

Feriyal: We don't know Down syndrome that much and the society has a negative view about it. I want to know what was the reaction of your family and friends towards it?

Farzad's mother: No one has told us anything disturbing to us yet, I mean like a normal child. They had doubt about it but they didn't say anything.

Scene 7: [brings up another psychedelic video clip of about 40 seconds showing an upside down view of a road as seen from a running vehicle, with accompanying music, churning the mind of the viewer as it ends with inverted buildings going round and round. It portrays the minds of parents with children who have Down syndrome.]

Scene 8: [returns to Bonyadi's office.]

Bonyadi: Before anything, we need to provide therapy to the parents because all parents, especially mothers, get shocked; mothers don't expect a child with Down syndrome or any other health problem.

Scene 9: [shows a conversation of Feriyal with Haji Zadeh, Down syndrome child psychologist at the Down Syndrome Institute in the backdrop of children with Down syndrome at the Institute engaged in different activities.]

Haji: Parental support is really important. Rehabilitation is a long and expensive process. It is not that the child lives for just one year and is then finished. Therefore, parental support from father, mother and other children, not only mentally but also economically, decides whether the rehabilitation could continue successfully or not.

Scene 10: [returns briefly to Bonyadi.]

Bonyadi: These children have delay in their growth and education; this delay could be solved through rehabilitation to decrease their differences with other normal children;

Scene 11: [begins with another psychedelic video clip. This one is just 8 seconds long, and shows a silent fast forward of the path taken by Feriyal from the road into the Institute, up the stairs and into the room where Haji sits. It ends with Haji receiving Feriyal with a handshake. A conversation between them follows.]

Feriyal: The biggest challenge is for the parents, because living with this kind of a problem is really hard. But how is it that some of them are able to overcome and some are not?

Haji: It is really important that this child is the first, second or third one; this means the mother is young, because many of the mothers here are in their 20s when they are expecting their first child. Again, a mother whose first child is born with Down syndrome would be more disappointed than one who is faced with her second child having this condition.

Scene 12: [shows Mohammad's house, with his parents seated facing an invisible Feriyal, with whom they are in conversation.]

Mohammad's mother: Mohammad's father and myself thought that he is a normal child. We treat him like we treat our other children. Parents should be together; not only father or only mother alone; it is impossible to do this alone. For example, if you want to lift this table you need to do it with someone's help, If I do this alone, I will hurt my back.

Scene 13: [brings Farzad's parents back.]

Farzad's mother: My husband never left me alone from the very first steps, I have been working with Farzad at home and his father helps him outside with his therapies and classes. Farzad himself also has been really supportive. I mean, from the first time that he talked we encouraged him and he said his second and other words; he is really great! My other children are very supportive as well.

Scene 14: [goes back to Mohammad's house.]

Mohammad's mother: The other children should understand that we have a child that has his own problems and needs help. Fortunately, our children were really supportive. I mean, when Mohammad was a child, as soon as he woke up three other faces were fighting to hold him first.

Mohammad's father: It's true sometimes they say that these children have a problem. But I think, I mean I recognized after these 24 years, that the main problem is with the parents themselves. There is a supervision organization in Iranshah street where the parents need to introduce themselves and choose a testamentary guardian for the child with Down syndrome. The first person they choose is the father.

Scene 15: [returns to Farzad's parents. During the latter half of the conversation, they both get emotional. Farzad's mother sobs loudly and father cannot hide his sorrow.]

Farzad's father: I think that our health organizations should works a lot with the parents who have this kind of child. I mean, they need to give them therapy and educate them.

Farzad's father: I'm always with Farzad in school and in his classes and I see that parents need more therapy than the children. If parents don't have good mental health they cannot educate these children properly, right? They are mostly depressed without hope. Several parents in the Institute whose children are younger than Farzad wonder when they see him, "Could our children be like Farzad?" I mean, he is their ideal. Their expectation is so low; they don't say they want their child to be normal, they just want their child to talk. We don't have that much expectation ... I don't know...

Scene 16: [starts with a video clip of Farzad working with his art teacher, showing total focus as well as childish emotions. This is interspersed with a parallel video that is a mix of natural scenery and kaleidoscopic designs. A high-pitched vernacular song in female voice plays all through. Towards the end, a small boy with Down syndrome (Taha Namazi) having long hair is seen buying bread from the baker. The background song stops and Taha is shown singing a nursery rhyme along with an elder.]

Elder: Wow where are you? Did you buy bread?

Taha: Yes I bought bread; I bought it this morning.

Elder: So where did you get the bread?

Taha: From the bakery.

Elder: What did you say to the baker?

Both: Baker, give me bread, please. I love you. Would you give me bread?

Scene 17: [changes to Mohammad's residence, showing his parents.]

Mohammad's father: I was going to the swimming pool - the Enghelab swimming pool. I was also bringing Mohammad there everyday. He came with me for about three months without touching the water and just kept watching. I didn't say anything at all; I just left him alone. After three or four months I was swimming to the other side and on the way back I saw him near the pool with his feet in the water. I didn't say anything again. It passed like this for two weeks until one day while swimming I saw him in the water. I asked for a trainer for him. I haven't left him alone from that day. And from then till now, for the 10 or 12 years that he has been swimming, I don't allow him to swim without his trainer.

Mohammad's mother: When he got a gold medal he really felt encouraged. You know he is the first Iranian swimmer to get a gold medal, I mean outside of Iran. We don't have anyone who got a gold medal yet.

Scene 18: [changes to show Farzad's parents. Both look emotionally drained out. During the conversation they both cry – the father sobbing loudly. There is silence for several seconds.]

Feriyal: How do you imagine Farzad's future?

Farzad's father: I just want that Farzad should be able to protect himself in society. Our only concern is his tomorrow. In this wild society ... we are in an age where we don't know about tomorrow. What would he do without us? We just want ... we hope that we can teach him to be independent. I hope we could make it possible. This is the reason that we are working on him.

Scene 19: [shows Feriyal in conversation with Mohammad in his home, looking at the medals and trophies he has won.]

Feriyal: You see, parents always force you to go to different classes, like swimming, gym, etc.; but I never could get a medal in anything. How could you do what I couldn't?

Mohammad: They send me to swimming and also futsal (running). That's all.

Feriyal: You also really wanted to get there. right?

Mohammad: For swimming yes, but it was a little hard for futsal. This is world gold medal with flower that I have. I have two world gold medals; one is for walking on ice in Idaho with its picture...for Mena, For Abu Dhabi, North of Africa. I have two gold medals with silver and the appreciation. The last one is for the Athens World Special Olympics that I got silver.

Feriyal: In what?

Mohammad: In walking on ice.

Feriyal: Which one is this? Where is this from?

Mohammad: This is for Athens.

Feriyal: For swimming?

Mohammad: Yeah.

Feriyal: What makes you so much strong?

Mohammad: I drink a lot of milk everyday, which makes me strong.

[The scene ends with laughter. Credits follow.]