

**A Participatory Assessment of the Down Syndrome Storyline
in *Páginas da Vida*, a Brazilian Telenovela**



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A Qualitative Assessment Report

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Executive Summary

The present report documents the results of focus group discussions and a participatory assessment exercise (participatory sketching), conducted in Rio de Janeiro, Brazil in November, 2006 to gauge how avid viewers of *Paginas da Vida* ("Pages of Life"), a popular TV Globo *telenovela* with a storyline on Down Syndrome, engaged with the program, deriving personal meanings from its plot, characters, and educational messages.

The results of the present qualitative report are not meant to be generalized to a regular population of *Paginas da Vida* audience members. Our research, at best, can suggest how certain (self-selected) viewers of the *telenovela* engaged with, and reflected upon, the content of the program, providing rich descriptive insights that cannot be gained from traditional, quantitative impact evaluations.

Three broad research questions guided the present study. These questions, and their respective answers -- gleaned from our focus group interviews and participatory sketching activity, are provided below.

Research question #1: *To what degree is the subject of Down Syndrome discussed in Brazil? To what extent is it part of the public discourse?*

Our focus group participants believed that disability topics (like Down Syndrome) had not received the media and public exposure in Brazil that they deserved. However, they were quick to point out that the public discourse on disability issues was getting better, and popular *telenovelas* like *Paginas da Vida* contributed greatly toward this realization.

Research question #2: *To what extent did the storyline and characters of Paginas da Vida accurately portray the lives of people with Down Syndrome and their families?*

Our focus group participants felt that the *telenovela* did, to some extent, portray the physical and care-giving aspects of Down Syndrome in a realistic manner. However, they emphasized that the reality of people living with Down Syndrome should also have been shown for households that were both poor and lower-middle class. They believed that Clara's middle-to-upper class background may have misled the audience; the kind of personal care that Clara received, the less privileged DS patients could not receive.

Research question #3 asked: *What influence did the telenovela have on you, especially in terms of its portrayal of Down Syndrome?*

The professionals working to address the needs of those with Down Syndrome and other disabilities believed that *Paginas da Vida* played a key role in bringing these "neglected" issues to the fore. Through popular screen characters, awareness about Down Syndrome and such disabilities was raised, and hope and compassion were generated for the presently disabled to

lead a higher quality of life. The metaphor of a “growing tree,” “the rising sun”, and “the budding flowers” expressed the sentiment that the telenovela was an important step in the right direction, while quite a bit of distance was yet to be charted.

The parents of children with Down Syndrome believed that *Paginas da Vida* played a key role in depicting their lives (as caregivers) and the lives of their disabled children with care and sensitivity. They repeatedly highlighted how the *telenovela* served as a door, bringing in new information, possibilities, and understandings, especially between and among those who were on the “inside” (those dealing with Down Syndrome) and those on the outside (friends, relatives, and colleagues). They believed that the *telenovela* helped audience members to appreciate that those with disabilities (such as Down Syndrome) can lead a fairly normal, if not completely normal, quality of life.

A Participatory Assessment of the Down Syndrome Storyline in *Paginas da Vida*, a Brazilian *Telenovela*¹

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Let us acknowledge upfront that the results of the present qualitative report are not meant to be generalized to a regular population of *Paginas da Vida* audience members. Our research, at best, can suggest how certain (self-selected) viewers of the *telenovela* engaged with, and reflected upon, the content of the program, providing rich descriptive insights that cannot be gained from traditional, quantitative impact evaluations.

The present report describes the *Paginas da Vida* project drawing upon the framework of entertainment-education, and the Brazilian experience of using *telenovelas* for social merchandizing. We list the research questions guiding the present research, discuss our focus group and participatory methods of data-collection, present our key results, and raise certain implications for employing participatory methods in the assessment of entertainment-education programs.

Entertainment-Education, Social Merchandizing, and *Paginas da Vida*

Paginas da Vida was a 203 episode *telenovela* broadcast on TV Globo from July 10, 2006 to March 3, 2007. Written by the noted 73-year old Manoel Carlos², the scriptwriter of eight previous TV Globo popular *telenovelas*, it was broadcast six days a week (Monday through Saturday) in the one-hour prime-time slot of 9 p.m. *Paginas da Vida* purposely featured (among other issues) a storyline on Down Syndrome (DS), representing an example of Globo's unique approach to entertainment-education: the social merchandizing approach.

Entertainment-education is defined as the intentional placement of educational content in entertainment messages to influence knowledge, attitudes, social norms, and behavioral practices of audience members (Singhal & Rogers, 1999). Entertainment-education is not a theory of communication, but rather a strategy used to disseminate ideas to bring about behavioral and social change.

The entertainment-education strategy in communication embodies itself in multiple ways. A highly popular genre for E-E is the lone serialized radio and television drama, purposely designed to promote certain educational values (Singhal & Rogers, 2002; Singhal, Cody, Rogers, & Sabido, 2004). The Soul City Institute of Health and Development Communication in South Africa uses a highly sophisticated, ongoing, multi media edutainment approach to reach audience members through prime-time television dramas (e.g. *Soul City* and *Soul Buddyz*), radio dramas in multiple languages, serialized stories in newspapers, life style manuals, and various advocacy and social mobilization activities. In the U.S., Hollywood lobbyists, the Centers for Disease Control

and Prevention, NGOs, and academic institutions work with producers of prime-time and daytime serials to inject an educational storyline in an ongoing television serial (Beck, 2004). In Brazil, TV Globo, the world's largest producer of television drama, achieves audience ratings of close to 60 percent for its prime-time *telenovela* fare, tackling educational issues through a unique E-E strategy called "social merchandizing" (Pastina, Patel, & Schiavo, 2004).

Social merchandizing involves the purposeful insertion of social and educational issues in the ongoing storyline of a prime-time Brazilian *telenovela*. As commercial marketers insert product images (i.e., product placement) into movies and television programs,³ TV Globo's scriptwriters place messages with social and political undertones in the *telenovela*'s storyline, making it a uniquely Brazilian E-E genre. A trend-setter for this genre was *Beto Rockefeller* (1968-69) that told the story of a man who sold shoes for a living but pretended to be a millionaire, socializing with the high and mighty⁴. The use of colloquial speech patterns, a realistic contemporary setting, and the toning down of artificial, tear-jerking melodrama distinguished *Beto Rockefeller* from the formulaic Latin American *telenovela* genre. A hit with the Brazilian audience, and broadcast for some 13 months (as compared to the usual run of 6 to 8 months), *Beto Rockefeller*'s success impressed upon TV Globo the importance of investing heavily in high production values, including incorporation of outdoor scenes, and relying heavily on Brazilian writers so that the topics, dialogues, and settings resonated with the Brazilian audiences.⁵

Beginning in the mid-1980s, after a two decade run with a military government that promoted a nationalization of the country's culture, Globo encouraged its *telenovela* scriptwriters to more brazenly delve into topics of social and political significance. Topics such as free elections and citizenship, worker rights and labor strikes, corruption and reform, which could not be discussed when the military government was in power, found utterance. Scriptwriters increasingly portrayed the local, daily struggles of Brazilian society within a melodramatic genre. By incorporating popular language and using colloquial expressions, vernacular, and metaphors rooted in the daily life, Globo turned the Brazilian *telenovela* from being a purely entertainment genre (in the tradition of the formulaic Latin American *telenovela*) into a popular platform for public discourse on social and political issues.

By the mid-1990s, social merchandizing had become an integral part of Globo's *telenovela* production, and a formal unit on social merchandizing was established in the corporation. As long as audience ratings were sustained, scriptwriters could address varied issues: for example, racial equality and homosexuality (*Próxima Vítima*, 1994), missing children (*Explode Coração*, 1995), land reform and political morality (*O Rei do Gado*, 1996-1997), and coping with leukemia (*Lazos de Sangre*, 2000). More recently, lobbying efforts by different organizations (e.g. Population Media Center in Vermont, Comunicarte and Fiocruz Fundação in Brazil) have influenced social merchandizing agendas on Globo's *telenovelas*. By 2006, Comunicarte estimates that it influenced incorporation of social merchandizing on some 85 Globo *telenovelas*. Further, Comunicarte has monitored each of Globo's prime-time *telenovelas* since 1995, identifying the number of social merchandizing scenes and situations. By 2005, some 10,646 social scenes were identified on topics ranging from sexual and reproductive health, to gender relations, to drug abuse.

For reasons unknown, the social merchandizing approach on Globo has not been systematically or formally evaluated (Pastina, Patel, & Schiavo, 2004). However, there exists plenty of anecdotal evidence to suggest that this approach pays social dividends: for example, as

the fictional mother in *Explode Coração* (1995) met with real-life mothers of missing children at a weekly protest in Rio de Janeiro, some 75 children were reunited with their parents over the course of the *telenovela*'s duration (Epstein & Padgett, 1997). Also, in 2000, when Camilla, the protagonist on *Lazos de Sangre* ("Blood Ties"), a popular Brazilian *telenovela*, was diagnosed with leukemia, the Brazilian National Registry of Bone Marrow Donors reported that new donor registrations increased by 45 times: from about 20 a month, to 900 a month (TV Globo, 2003).

***Páginas da Vida*'s Down Syndrome Storyline**

The plot of *Páginas da Vida* was designed around several intersecting storylines, one of which focused on Down Syndrome⁶.

Nanda (short for Fernanda), a Brazilian student of Art History in Amsterdam, falls in love with another student called Leo (short for Leonardo), and becomes pregnant after she moves in with him on his houseboat. The sole child of wealthy parents, Leo is terrified about his father's anticipated reaction to Nanda's pregnancy, and asks her to abort the child. When Nanda refuses, Leo gives her a large sum of money and disappears (years later he would surface in Brazil).

Abandoned by Leo, Nanda returns to Brazil and faces a series of tragic events. Hit by a car, Nanda is taken to the hospital where the obstetrician Dr. Helena (played by Regina Duarte) is able to save her twins, but cannot save her life. One of the newborn girls, Clara, is identified with Down Syndrome (DS), a genetic disorder (occurring about 1 per 800 births), which often results in reduced cognitive ability and poor muscle tone. Nanda's mother, the cold-hearted Marta, rejects her granddaughter, having no idea that early childhood interventions, pre-screenings, medical treatment, a nurturing family environment, and vocational training can significantly improve the quality of life of those with DS.

Longing to be a mother (her only child had died previously), Helena adopts the unwanted Clara, raising her with love and care. Clara (played by Joana Morcazel) is Francisco's twin sister and does not know the existence of her true family. Although a carrier of DS, Clara studies in a suburban school as per the wishes of her mother Helena who very openly favors the social inclusion of those with disabilities. As the storyline evolves, Clara and Helena encounter several people who stigmatize disabilities, raising an ongoing debate about the issue of disability throughout the course of the *telenovela*. Years later, when Leo (Clara and Francisco's father) surfaces in Brazil, Helena is caught in a bind: Should she disclose that his daughter is under her care?

In essence, it was through Clara's character, and Helena's care for her, that the viewers learned about Down Syndrome, its physical ramifications, as also the stigma faced by those who are diagnosed with it. Through these main characters, *Páginas da Vida* was intended to spark reflection, conversations, and more compassionate actions about Down Syndrome and other disabilities.

While those were some of the intended objectives of *Páginas da Vida*, we do not know how the certain viewers engaged with the *telenovela*. Through our qualitative investigation, which included focus group discussions and participatory sketching (described later in this report), it became evident that some of these intended learning objectives were met.

Research Questions

In order to gauge the personal meanings that avid viewers of *Paginas da Vida* drew from its plot, characters, and educational messages, our focus group interviews and participatory assessment exercise centered on asking the respondents the following three questions:

Research question #1 asked: *To what degree is the subject of Down Syndrome discussed in Brazil? To what extent is it part of the public discourse?*

Research question #2 asked: *To what extent did the storyline and characters of Paginas da Vida accurately portray the lives of people with Down Syndrome and their families?*

Research question #3 asked: *What influence did the telenovela have on you, especially in terms of its portrayal of Down Syndrome?*

Participatory Assessment and Focus Groups

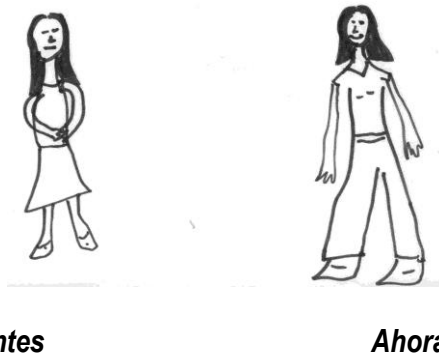
In recent years, participatory sketching has emerged as novel, audience-centered, and low-cost qualitative methodology for assessing the meanings that audience members of entertainment-education (E-E) programs derive from their engagement with the mass media text (Singhal & Devi, 2003; Singhal & Rattine-Flaherty, 2006; Singhal, Rattine-Flaherty, & Mayer, 2006; Singhal, Greiner, & Hurlburt, 2006). Such participatory methodologies offer a different perspective on audience engagement than, for instance, can be gathered through survey data⁷.

The inspiration for participatory sketching (or photography) comes from the work of noted Brazilian educator, Paulo Freire. In 1973, while conducting a literacy project in a barrio of Lima, Peru, a team led by Freire (author of the seminal 1970 book *Pedagogy of the Oppressed*), asked people questions in Spanish, but requested the answers in photographs. When the question "What is exploitation?" was asked, people photographed a landlord, grocer, or a policeman (Boal, 1979, p. 123). One child took a photo of a nail on a wall. It made no sense to adults, but other children were in strong agreement. The ensuing discussions showed that many young boys of that neighborhood worked as shoe-shiners. Their clients were mainly in the city. As their shoe-shine boxes were too heavy for them to carry, these boys, rented a nail on a wall (usually in a shop), where they could hang their boxes for the night. To them, that nail on the wall represented "exploitation." The "nail on the wall" photograph spurred widespread discussions in the Peruvian barrio about other forms of institutionalized exploitation, including ways to overcome them.

Drawing upon Paulo Freire's work with participatory photography in Peru, researchers have employed participatory sketching as a method to obtain rich, nuanced narratives from audience members of E-E programs. For instance, one of the present authors employed the participatory sketching methodology to assess the effects of an entertainment-education radio soap opera initiative in the Philippines (Singhal, Rattine-Flaherty, & Mayer, 2006) and also to assess the effects of another radio initiative in the Peruvian Amazon, spearheaded by Minga Perú, a non-governmental organization that promotes gender equality and reproductive health (see (Singhal & Rattine-Flaherty, 2006). For over four years now, Minga Perú has broadcast – three times a week -- a popular radio program, *Bienvenida Salud* (Welcome Health) in the Amazonas, and dove-tailed

the E-E broadcasts with several community-based empowerment activities for local women (Singhal & Rattine-Flaherty, 2006). In 2005, using plain paper and colored markers, some 30 avid women viewers of *Bienvenida Salud* were asked to sketch out their perceptions of Minga Perú's contributions to reproductive health, gender equality, and social change. For instance, one of the questions posed was: "How has my life changed as a consequence of listening to *Bienvenida Salud* and participating in community-based activities of Minga Perú?" Participants were asked to draw two pictures – one to sketch how their life was some five years ago (i.e. *antes*, in the past), and how their life is today (i.e. *ahora*, now).

The *antes* and *ahora* sketches of Emira, a 21-year old, including her narrative, was highly revealing:



Emira noted: "This is my early life. I didn't know how worthy I was; I was ashamed, I was sad. Now my personal life has changed, I feel myself as being capable of exerting a public function; I don't feel ashamed any more, I don't have fear. I am proud of my body -- my femininity. Before, I didn't want to cut my hair but when I went to live to the city, I cut them. With the trousers it was the same. Now I feel capable to wear trousers; previously I wore loose clothes. The same with the shoes, now I wear high heels."

Emira's sketch and its accompanying narrative provided a highly rich, highly poignant, and highly textured/nuanced insight on the long-term effects of E-E initiatives on certain audience members. As noted previously, such insights are difficult, if not impossible, to obtain through structured personal interview surveys.

As both the Peruvian examples of participatory photography and sketching demonstrate, in privileging visual forms of expression, E-E researchers position themselves to question the dominant hegemony of textocentrism that legitimizes the lettered, literate, and text-based ways of knowing (Conquergood, 2002). Participatory sketching and photography both validate other non-textual ways of knowing by privileging the performative dimensions of sketches and photographs.

Inspired by this Freirean technique and Conquergood's (2002) call for incorporating more visual, performative methods, our assessment of *Paginas da Vida* in Brazil included participatory sketching activities, complemented with focus group discussions.

Focus Groups and Participatory Sketching for *Paginas da Vida*.

Focus group interviews were carried out in Rio de Janeiro, on the 28th and 29th of November, 2006, in the headquarters of the FUNLAR (The Francisco de Paula Municipal Foundation for Home Schools) with two groups of participants: (1) Nine professionals who work with people with Down Syndrome (psychologists, social workers, social educators, and NGO representatives), and (2) 12 parents (11 mothers and one father) of children with Down Syndrome in the city of the Rio de Janeiro. Discussion questions centered around how participants felt while watching the difficulties and joys expressed by characters such as Clara (the young girl in the telenovela who had Down Syndrome), her mother, Helena, and the characters they interacted with. The participants of the focus groups also engaged in a participatory sketching exercise.

The participants of the focus groups were selected in accordance with criteria previously outlined by the research planning team comprising of representatives from Ohio University, PMC, and Comunicarte: Participants must have been avid viewers of *Paginas da Vida* and must have been involved with Down Syndrome, either through doing professional work in the field, or being a parent of a child with Down Syndrome. A partnership with FUNLAR was established, as they provide various public services to individuals (and their families) with disabilities, including Down Syndrome, in Rio de Janeiro.

The focus group discussions were conducted in rooms with both audio and video equipment so they could be recorded. Each focus group session included a moderator and two observers. The moderator facilitated the dialogue. One of the observers was responsible for conducting and facilitating the participatory sketching exercise, and took a first step at analyzing the collected data. Each focus group session lasted for approximately two hours.

As part of the participatory sketching exercise, we asked our respondents: *What influence did the telenovela have on you, especially in terms of its portrayal of Down Syndrome?* However, rather than having them respond orally to our query, we asked them instead to sketch their responses on white cardstock using colored pencils.

The participants were encouraged to draw whatever they wanted, regardless of their drawing ability, and no rigid time limits were set in order to not rush them. This participatory sketching activity with 21 respondents yielded an equal number of drawings. After the sketches were completed, individuals responsible for the drawing narrated what the sketch was about, including how it answered the posed question, in front of the entire group. These narrations were translated for the purposes of this report from Portuguese to English.

Public Discourse on Down Syndrome

Research question #1 asked: *To what degree is the subject of Down Syndrome discussed in Brazil? To what extent is it part of the public discourse?*⁸

A majority of the professional participants (psychologists, social workers, social educators, and NGO representatives) believed that the subject of Down Syndrome is rarely discussed in Brazil. Many noted that they themselves learned about this genetic disorder when they began to

encounter people with Down Syndrome in their professional lives: "I find that Down Syndrome is rarely discussed; those living with this condition are hidden and little is divulged. Another participant noted: "The subject of Down Syndrome is not discussed enough despite of the efforts of the families and associations working with Down Syndrome. More recently parents have started to count on support from the government. I have worked in this area for 20 years and recently learned about the association SINDOWN." This participant then noted the importance of raising this topic on the media and public agenda: "Down Syndrome is discussed very little, this is why the media is important. We have the *telenovela* now, but it is necessary that it continue to be discussed more."

However, the professional participants acknowledged that the public and media discourse on people with disabilities was improving, and the *telenovela* was an important contributing factor. One participant poignantly noted how times were changing: "I remember in a post-graduate course I took many years ago, the question was asked: in an airplane disaster, who you would save? The participants in this course were professionals who worked in health. The majority said they would not save the people with Down Syndrome. I was shocked because here we are speaking of the paradigm of social inclusion, and 20 out of 26 people would not save the people with Down Syndrome. However, now messages about Down Syndrome are widespread; TV Globo is speaking about it, and it is now in the theater, the cinema, and the schools. What I witnessed before in that post-graduation course, today I am certain that those people would be ashamed of what they had said."

Another participant also emphasized the importance of accurate and sensitive media representations of such issues on television: "On one hand, I see that already 25 years have passed, and barely any progress has been made. When I see the *telenovela*, it is wonderful, but we should invest more in television and other media. When I worked as a faculty member, I saw a couple separating because they discovered that one of them had a genetic problem. The couple stayed in that paranoia of wanting to understand why they had a child that was 'different.' Through this experience, I realized that we should invest in the media to show accurately what Down Syndrome is. This will create a floodgate, showing the public the capacity that people with Down Syndrome have. I see that the *telenovela* is going down a good road to show this, especially as it shows it in an engaging way."

Another participant expressed his hope that disability topics would become part of the mainstream discourse in Brazil: "I am a little more optimistic....I am part of the (Down Syndrome) movement and related associations, and I have already met many parents who are working not just for their children, but also for the future generations of children with Down Syndrome. What we have not had yet is a society-wide change in mentality, which may take 100 years. The *telenovela* boldly brings forward the important question of the image of the child with Down Syndrome. Because the character (Clara) is shown as dependable, she demonstrates the capacity of people with Down Syndrome."

In sum, our focus group participants acknowledged that disability topics (like Down Syndrome) had not received the media and public exposure that they deserved. But they were also quick to point out that the public discourse on such disability issues was getting better, and popular *telenovelas* like *Paginas da Vida* contributed greatly toward this realization.

Portrayal of Down Syndrome: How Real?

Research question #2 asked: *To what extent did the storyline and characters of *Paginas da Vida* accurately portray the lives of people with Down Syndrome and their families?*⁹

Some participants noted that the *telenovela* portrayed the reality of those with Down Syndrome independent of their socio-economic status: "Clara is rich but still suffered prejudice."

However, many participants thought that the *telenovela* could have done a better job in portraying other salient aspects of DS: "People may not identify with the *telenovela* because she (Clara) lives in the middle class. The *telenovela* does not show economic diversity." Another participant echoed this sentiment while realizing that a *telenovela* cannot be all things to all: "I do not agree with the *telenovela*'s portrayal of Down Syndrome through the character Clara. Clara goes to a private school, has a private doctor, and goes to a private speech and vocational therapist. This does not reflect reality. Because she (Clara) is rich it becomes difficult to imagine poor children with Down Syndrome. I do not know a single person with Down Syndrome here in Brazil that has all the services that Clara has. In general, they are people with low income. They [TV Globo] should be applauded to show Down Syndrome, but it was not the way it mostly is."

Participants provided some other suggestions for enhancing relevance and realism for the viewing audience: "They should have had a mother who truly had a child with Down Syndrome [pointing out that Helena was not the biological mother of Clara]. Some participants asked the question: "Why do they only show Down Syndrome? Why not any other disability?"

Notwithstanding the various suggestions to make the DS storyline more realistic, participants seemed to be in agreement with this overarching sentiment: "From the moment that you put a person with a disability in a *telenovela*, it democratizes the information. Upon watching the *telenovela*, my daughter saw Clara and said: She is very pretty! I ask: before now, when would someone recognize beauty in one who is different? We live in a world where everyone should be equal; however, people are not accepted for their differences. I understand our distress, wanting to include all other syndromes and all other disabilities, but I find it very interesting that including a person with Down Syndrome creates questions about all disabilities."

In sum, our focus group participants felt that the *telenovela* did, to some extent, portray the physical and care-giving aspects of Down Syndrome in a realistic manner. However, they emphasized that the reality of people living with Down Syndrome should also have been shown for households that were both poor and lower-middle class. They believed that Clara's middle-to-upper class background may have misled the audience for the kind of personal care that Clara received the somewhat less privileged DS patients cannot expect to receive.

Influence of *Paginas da Vida*

Research question #3 asked: *What influence did the *telenovela* have on you, especially in terms of its portrayal of Down Syndrome?*

The above question was posed to participants in both groups: (1) the nine professionals (psychologists, social workers, social educators, and NGO representatives) who closely deal with

Down Syndrome, and (2) the 12 parents of children with Down Syndrome residing in Rio de Janeiro. The responses to this question were sought first through a sketch (i.e. visually), followed by the narration of the sketch in front of all group members. For the sake of organizational coherence, we first present the sketches and narrations of the professional participants, followed by those of parents.

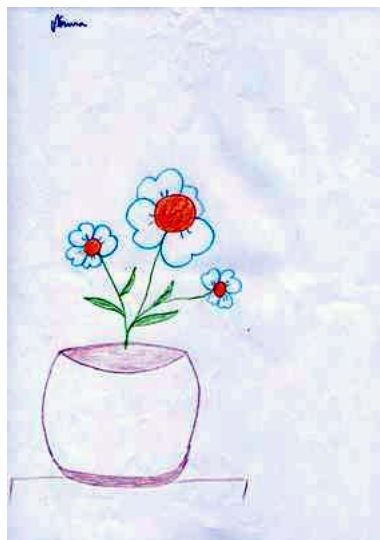
On Professionals

Our professional participants answered this question about the influence of *Páginas da Vida* in various ways.

Drawing a sketch of the various phases of development of a tree, beginning with the seed, one participant noted: “The telenovela was a small seed that will blossom and grow with the sun (of information) and rain (help from professionals). When it grows, the tree is going to generate fruit that will nourish the people, and the information itself [on Down Syndrome], if portrayed well, will form new opinions, and behaviors will change.”



Another participant drew a flower pot and noted: “You see three pretty flowers, but one of the petals is a little atrophied (the smaller one). The messages about Down Syndrome and other disabilities in *telenovelas* seem to be increasing and causing more debate, generating different opinions. However, it is still necessary to create a bigger base and more solid vehicle for these messages. For this reason, I did not finish the table in the drawing [on which the flower pot sits]. The subject of Down Syndrome can still be better explored and the information could be integrated at a broader level. The flowers are different, as we all are, and, like the flowers, everybody has their own beauty. The vase is disproportionate intentionally, because everything in life is a ‘little crooked’....it is up to us whether or not we see them with love.”



Another participant, Claudia, drew the sketch of Clara playing a park and noted: “Here Clara is playing with other children in the school, and her mother, Helena, is keeping an eye on her from far off. When I watched this scene in *Páginas da Vida* I realized the social inclusion of the girl with Down Syndrome was possible, something which could not happen four years ago when I started to work on this issue. I remember the insecure look on Helena’s face when she initially watched her daughter play with other children, but soon after that her concerns were alleviated.”

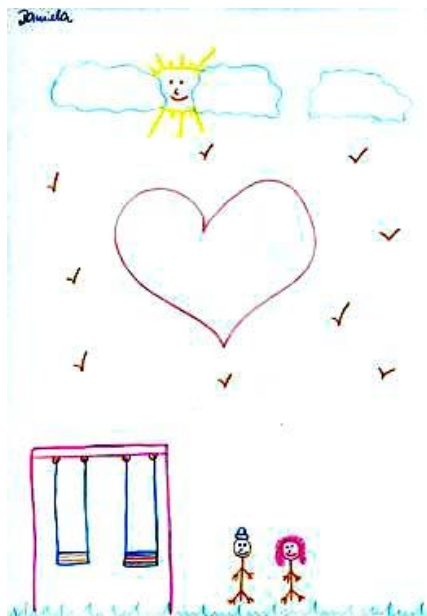


Another participant, Giãne, drew a child with Down Syndrome and narrated: “Here is a child with Down Syndrome inside a big heart that is located in a garden. The most important thing is that people with Down Syndrome are always in our hearts, and are given special attention. What most impacted me in the *telenovela* was the rejection that Clara suffered, and how they (people

with Down Syndrome) are misunderstood. I find that the *telenovela* reflected how professional social workers and others take care of children with Down Syndrome, improving their inclusion in society.”



Another professional participant drew Clara and her brother in the park, noting: “I like to see Clara playing in the park with her brother because it shows that they are equal. They are as normal as any children can be when they play. This promotes equality between non-disabled and disabled people.



Anne, another participant drew a rising sun and elaborated: “Here we see a sun with Down Syndrome rising on the horizon, and below the horizon are several layers of colors. The biggest impact of the *telenovela* was raising a series of questions related to Down Syndrome. Moreover, the image of a person with Down Syndrome on television, during prime time, opens a space for a new set of possibilities, which are represented in my drawing with the rainbow of colors. I feel

proud to see the work of TV Globo in the past years which has brought such issues to millions of people. In the rainbow, the red represents the opportunities that Clara has; to feel secure, to make her own choices, and be independent. The brown represents the land, and the reality that she (Clara) lives in, interacting with her family, health professionals, and people in school. The black color represents the difficulties that all people face, such as the fear of not being accepted in a school classroom....these are things that happen to people whether or not they have Down Syndrome. The birds in the sky represent the freedom that the universe of information gives to people....”



Marcia's sketch depicted people with different attributes and was narrated as follows: "Here are people with different characteristics. I find that the *telenovela* reaches various people, and its biggest possible impact is the possibility that it holds to knock down attitudinal barriers about difference between people, promoting a sense of equality between people. The sun in my drawing represents the idea that the sun reaches us all (the mother, the neighbor, Clara, the teacher) and we all are equal in this regard - the sun shines for all. The attitudinal barriers that the *telenovela* helps to influence deal with inclusion for those with Down Syndrome in school, the important role of teachers and the health professionals in their well-being, and the hidden capacities of people with Down Syndrome such as Clara.



Betina, a professional service provider for Down Syndrome children, presented her sketch (below) with the following narration: “For me the *telenovela*’s impact is the hopeful image that it portrays of excluded people, and of the professionals who work in the area. It also portrays the beautiful image of a capable child, and this is important for professionals like us because we are so accustomed to always seeing the ugly side of a disability (the parents who reject their child, the lack of public services for those who need them, etc.). It is important to see the beautiful side of a mother who overcomes the difficulties, and of a successful child, especially when it comes to the acquisition of language. From the *telenovela*, I learned how successful a child with Down Syndrome can potentially be.”



In sum, the professionals working to address the needs of those with Down Syndrome and other disabilities thought that *Páginas da Vida* played a key role in bringing these “neglected” issues to the fore. Through popular screen characters, awareness about Down Syndrome and such disabilities was raised, and hope and compassion were generated for the presently disabled to lead a higher quality of life. The metaphor of a “growing tree,” “the rising sun”, and “the budding

flowers” expressed the sentiment that the *telenovela* was an important step in the right direction, and quite a bit of distance was yet to be charted.

On Parents

Our 12 participants who were parents of children with Down Syndrome answered the question about the influence of *Paginas da Vida* – through sketches and accompanying narrations – in multiple ways, acknowledging that the *telenovela* had an important influence. Some parents, highly moved by the process of the sketching exercise, noted that the treatment of Down Syndrome into *Paginas da Vida*, had stirred them.

Pointing to the sketch of the boat, a parent noted: “The *telenovela* leads people to sail in the direction of a world in which the families of children with disabilities live. This is a world of love, with a special brilliance. The *telenovela* is leading people to see what happens in this world. The sun is here because it rises for everybody inside the little boat. The trees have fruit and everything that is good for people with disabilities is also good for other people.”



Marcia drew a sketch of four people in a house with their hearts connected and noted: “I drew Helena’s house, with Clara, her brother, and their maid. This is a united family, which is often not the reality of the majority of families that have a disabled person. The impression that it conveys in the *telenovela* is that such a family can exist happily.”



Another parent pointed to how the *telenovela* helped other family members to gain a better understanding of Down Syndrome: "I drew a house with my family in the northern part of Brazil watching television. You can see my father and my sister. They do not know my son personally, they only knew that he has Down Syndrome. The *telenovela* helped my family from the North discover who my son is, and realize that Down Syndrome is a fairly manageable situation to live with. Now I can finally explain to them how things are with us, because the *telenovela* depicts our lives. The only difference is that Clara, who has Down Syndrome in the *telenovela*, is a girl and my son is a boy. I explained to my family on the telephone how my son has Down Syndrome like Clara, but that he has already grown and developed and today he swims and engages in other activities. It was really wonderful to be able to do so!"



One of the parents did two drawings, side-by-side. She noted: "In the first one I am at home watching the *telenovela* and the telephone is close by, which is a rotary phone, like the one that appears next to Clara in the TV program. Many people (my immediate family, friends, and colleagues) called me for my comments on certain scenes. They would tell me what happened in the program, and ask opinion about certain scenes -- like the one scene in which the speech therapist explains how to stimulate oral mechanisms in infants with Down Syndrome. They asked me if that helped my child. In the second drawing, I drew Clara and my son in a classroom. It shows that they seem different from far away, but if you look close, they are as healthy as any other students. They are really not different."



One parent, Leila, highlighted the importance of the *telenovela* by noting: "The focus of my drawing is the door. There existed a world of Down Syndrome before my child was born, but he was on the other side. After he was born, a new world arose for me. The *telenovela* has opened the door of acceptance: of society and families, who did not know this world before."



Another parent drew two houses and said: “The clouds that I drew on top of the houses are because when I received the news that my child had Down Syndrome I felt that everything was dark. But then came the *telenovela* and it was almost like the sun comes out and showing you how to deal with this situation. The door that opened represents new information, attitudes, and behaviors, but mainly is a door of acceptance. The sun represents a bright light for parents and for people with Down Syndrome, and for others who do not know much about this disability.



And, finally, one parent drew two faces and provided the following poignant narration: “Here are two faces. There is an ugly face, with big ears, big eyes and poorly kept hair - a distorted vision of our children. There is also a prettier, more proportional face, more equivilant to reality. Still it lacks something. I left an empty space below, where I would like to draw a beautiful future. I find that children with disabilities are already accepted by other children, and these children are going to transform the adults (parents) who have the wrong vision. This will be a tranformation from the botton up, as it is not happening from the top down. The information that people now have about children with Down Syndrome, especially after the *telenovela*, is the most positive change that can be seen today.”



In sum, the parents of children with Down Syndrome believed that *Paginas da Vida* played a key role in highlighting their lives as caregivers, and the lives of their disabled children with care and sensitivity. They repeatedly highlighted how the *telenovela* served as a door, bringing in new information, possibilities, and understandings, especially between and among those who were on the “inside” (those dealing with Down Syndrome) and those on the outside (friends, relatives, and colleagues). They believed that the *telenovela* helped audience members to appreciate that those with disabilities (such as Down Syndrome) can achieve a high, if not completely normal, quality of life.

Summary and Conclusions

The present report documents the results of focus group discussions and a participatory sketching activity conducted in Rio de Janeiro, Brazil to gauge how avid viewers of *Paginas da Vida*, a popular *telenovela* with a storyline on Down Syndrome, engaged with the program, deriving personal meanings from its plot, characters, and educational messages.

Our focus group participants acknowledged that disability topics (like Down Syndrome) had not received the media and public exposure that they deserved. They were also quick to point out that the public discourse on such disability issues was getting better, and popular *telenovelas* like *Paginas da Vida* contributed greatly toward this realization.

Our focus group participants felt that the *telenovela* did, to some extent, portray the physical and care-giving aspects of Down Syndrome in a realistic manner. However, they emphasized that the reality of people living with Down Syndrome should also have been shown for households that were both poor and lower-middle class. They believed that Clara's middle-to-upper class background may have mislead the audience for the kind of personal care that Clara received the somewhat less privileged DS patients cannot expect to receive.

The professionals working to address the needs of those with Down Syndrome and other disabilities thought that *Paginas da Vida* played a key role in bringing these "neglected" issues to the fore. Through popular screen characters, awareness about Down Syndrome and such disabilities was raised, and hope and compassion were generated for the presently disabled to lead a higher quality of life. The metaphor of a "growing tree," "the rising sun", and "the budding flowers" expressed the sentiment that the *telenovela* was an important step in the right direction, and quite a bit of distance was yet to be charted.

The parents of children with Down Syndrome believed that *Paginas da Vida* played a key role in depicting their lives (as caregivers) and the lives of their disabled children with care and sensitivity. They repeatedly highlighted how the *telenovela* served as a door, bringing in new information, possibilities, and understandings, especially between and among those who were on the "inside" (those dealing with Down Syndrome) and those on the outside (friends, relatives, and colleagues). They believed that the *telenovela* helped audience members to appreciate that those with disabilities (such as Down Syndrome) can lead a fairly normal, if not completely normal, quality of life.

What implications does our work with participatory sketching have for researchers of entertainment-education initiatives? First, these participatory methods lie at the interface of theory, method, and praxis (see also Morphy & Banks, 1997). In taking stock of the sociology of visuals – whether in the form of sketches or photos – it is not difficult to discern the obvious conclusion: Almost all paintings, sketches, and photos are usually produced by "the powerful, the established, the male, the colonizer" to "portray the less powerful, less established, female, and colonized" (Harper, 1994, p. 408). Through participatory photography and sketching, E-E researchers hand over the means of visual production to the oppressed, the silent, and the muted. While recognizing that visuals allow the "oppressed" to make statements that are not possible by words, E-E researchers should remember that all sketches, paintings, and photographs are socially and

technically constructed (Harper, 1994). Thus it is as important to foreground the absence of particular characters or scenes, as it is to explicate what is present.

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Endnotes

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² Along with associate Fausto Galvao and in collaboration with a team of assistants, including Maria Carolina, Julian Peres, Angela Chaves, and Daisy Chaves.

³ La Pastina (2001); Melo (1989).

⁴ See Lopez (1995); Mazziotti (1992); Pastina, Patel, and Schiavo (2004).

⁵ McAnany (1984); Straubhaar (1982, 1996).

⁶ Several other social issues were merchandized on *Paginas da Vida*. For instance, one of the characters Anna is an anorexic who wants her daughter, Giselle, to be a ballerina and very thin. There is also a nun, sister Lavinia, who will get involved with an HIV-positive patient in the hospital where she works. And so on.

⁷ Clearly, all methods of data-collection – whether quantitative or qualitative -- have their respective strengths and weaknesses. Further, the implementation of any method in the field is steeped in the grounded and situated realities of the respondents and their context.

⁸ This research question was primarily posed in the focus group with professionals (psychologists, social workers, social educators, and NGO representatives) who dealt with Down Syndrome on a day to day basis and are in a position to gauge the public perception toward this topic.

⁹ This research question was also primarily posed to professionals (psychologists, social workers, social educators, and NGO representatives) who deal with Down Syndrome on a day to day basis and meet a wide variety of DS patients and families.