

This article was downloaded by: 10.3.97.143

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Publisher: *Routledge*

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: 5 Howick Place, London SW1P 1WG, UK



The Routledge Companion to Disability and Media

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Pages of Life

Publication details

<https://www.routledgehandbooks.com/doi/10.4324/9781315716008-20>

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Published online on: 20 Nov 2019

How to cite :- Patricia Almeida. 20 Nov 2019, *Pages of Life from: The Routledge Companion to Disability and Media* Routledge

Accessed on: 22 Mar 2023

<https://www.routledgehandbooks.com/doi/10.4324/9781315716008-20>

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PAGES OF LIFE

Using a Telenovela to Promote the Inclusion of Students with Disabilities in Brazil

Patricia Almeida

Telenovelas in Latin America, television soap operas with a “contained story arc that ends after a few seasons” airing every week day,¹ are a significant part of Brazilian popular culture and this chapter explores how one telenovela, *Pages of Life* (*Páginas da Vida*),² used a plot about a child with Down syndrome³ to further the discussion of inclusion of children with disabilities in education.⁴ This telenovela is one of the most popular Brazilian telenovelas, according to IMDb ratings,⁵ and also based on viewing ratings published by IBOPE.⁶ The storyline was a major hit in the telenovela genre with episodes featuring the child with Down syndrome, with the last chapter reaching an audience of 53 rating points according to IBOPE (76 percent of TV sets in use in Brazil tuned into the channel).⁷

Research conducted at BEMFAM family planning clinics in 2006 and 2007 found that 83.3 percent of women viewed the show at least twice per week.⁸ More importantly for this chapter, further research of 201 respondents who were affiliated with FUNLAR (the Brazilian national Down syndrome association) showed that the storyline led to 72.6 percent of those surveyed reporting that their knowledge of Down syndrome increased by watching *Pages of Life*.⁹

Telenovelas have a long history in Brazil. The first one went on air, live, in 1951, twice a week. In 1963, telenovelas started to be shown every weekday night.¹⁰ In the 1970s, when TV sets became more available to the general public, telenovelas became the most watched programs by all segments of gender and age groups in Brazil.¹¹ A 2015 representative sample study of TV viewers in 11 Latin American countries reported that telenovelas continue to be popular and ranked at number one with audiences in Brazil, Panama, Uruguay and Paraguay.¹²

Because of this enormous popularity, telenovelas became powerful trendsetters, leading to new slang expressions, fashion accessories or favorite haircuts. The first product placement in a telenovela was in 1973, in *Steel Horse* (*Cavalo de Aço*),¹³ a telenovela on TV Globo, the Brazilian network with the highest viewership. The show strategically placed a bottle of cognac, with its label turned towards the camera, so that the audience could see the main character drinking that brand. This type of product placement allows viewers to interact with a product through their favorite telenovela character.¹⁴

Similarly, the topics featured in telenovela plots are discussed in casual conversations throughout Brazil: at the dinner table, on radio shows, at work, at school. Telenovelas began to be understood as an effective way to promote all kinds of messages to the general public. In 1994, Silvio de Abreu was the first writer to intentionally include a social issue in a telenovela plot in an attempt to educate the TV audience. His telenovela *The Next Victim* (*A Próxima Vítima*)¹⁵ presented audience members with issues involving homosexuality and racial discrimination.

A soap opera is educational when it raises discussions about Brazilian society to a relatively uninformed public. It raises subjects that, despite being part of everyday life, are not understood or discussed. Everyone who watches, and even those who do not watch, are led to reflect about those issues. I think soaps are one step ahead of society.¹⁶

Using a telenovela to educate an audience about social issues in society is a form of social merchandising.

Social merchandising is the intentional insertion of social issues and educational messages in soap opera plots and other TV programs. As a strategy for change in attitude and for the adoption of new behavior, social merchandising is one of the most effective tools, as it reaches the audience in an entertaining way, disseminating new attitudes and practice. Social themes are tackled as an integral part of the stories, associated to characters in an educational and positive way.¹⁷

After Silvio de Abreu wrote his telenovela script about racial diversity and the LGBT community in 1994, other TV writers began using their scripts to focus attention on topics such as how to do a self-examination to detect breast cancer and explaining what HIV is, for example. In addition, the inclusion of content about these educational topics reflected well on the TV channels, illustrating their commitment to being socially responsible.

Inclusive Education in Brazil

Formal education for children with disabilities in Brazil started in 1854, with the creation of the Institute of Blind Boys and the Institute for the Deaf and Dumb, in 1857 in Rio de Janeiro.¹⁸ In 1874, children with intellectual disabilities were taught at the Juliano Moreira Hospital, in Salvador, Bahia, with other schools being created mostly in Rio de Janeiro and São Paulo, Brazil's most populated cities.

In 1949, about 40 schools in Brazil enrolled children with intellectual disabilities. By 1959 the number had increased to 190, 77 percent of them public schools.¹⁹ In 1973 the Ministry of Education created a center to manage special education in the country.²⁰

In 1988, Brazil's new Constitution established "mandatory fundamental education, including to those who did not have access to school at a proper age, and specialized education services to students with disabilities, preferably in the general school system."²¹ Nevertheless, until the 1990s, children with disabilities were mostly educated in segregated schools and did not have contact with non-disabled peers.²² In 1994, Brazilian education authorities committed to using inclusive education practices as laid out in the *Salamanca Statement on Principles, Policy and Practice in Special Needs Education and a Framework for Action*, which had been adopted at the UNESCO Conference in Salamanca, Spain in the same year.²³ For Brazil that meant shifting disabled students from special schools into regular schools.

The Brazilian education system is composed of public and private schools, with 81.7 percent of students attending public and 18.3 percent attending private schools.²⁴ The federal government regulates the system through the Ministry of Education, which provides funding and educational guidelines. Individual states and municipalities are responsible for implementing and enforcing these guidelines.²⁵

With over 90 percent of students with disabilities attending regular schools in 2014, compared with 13 percent in 1998, the Brazilian education system is considered a model for inclusive education in Latin America.²⁶ The results reflect the constant action of the social movement and an open Ministry of Education in the past two decades. Nevertheless, according to experts, the quality of education needs improvement and public and private schools still have a long way to go when it comes to physical accessibility, resource rooms, trained teachers and assistants to make them effective for students with special learning needs.²⁷ Though mandatory,²⁸ public preschools

and kindergartens have few spaces and are reportedly not prepared to include children with disabilities. Families need reassurance alongside consistent and informed support by the state and their communities.²⁹ Teaching students with special learning needs was identified as one of the areas of greatest need for development according to teachers in Brazil, as in almost all other countries evaluated by Talis, the OECD “Teaching and Learning International Survey” held in 34 countries in 2013.³⁰

The largest Brazilian institution providing special education, the Association of Parents and Friends of the Exceptionals (APAE), offers services in more than 2,000 districts in the country, so the idea of transitioning students with disabilities from segregated schools to the regular classrooms faced much resistance from parents, teachers and groups like APAE.

Created by parents of children with disabilities in 1954, APAE was inspired by Beatrice and George W. Bemis, members of the American diplomatic service, who moved to Rio de Janeiro with their daughter Caroline, who had Down syndrome. George Bemis who had served as vice president of the US National Association for Retarded Children (later renamed the Arc),³¹ and Beatrice Bemis became actively involved in founding APAE’s first school in Brazil. In 1954, the association had two classes with 20 children in total. By 1962, APAE chapters from 16 different cities in Brazil joined together to start a federation. With the absence of Brazilian states to provide education for students with disabilities, the federal government started to partly fund these charitable groups. In 2013, the APAE Federation reported assistance to more than 240,000 Brazilian students, most with intellectual and multiple disabilities, in more than 2,000 school districts.³² Since the adoption of Salamanca Declaration, APAEs have resisted the idea that students with disabilities can be educated in regular schools. They accused pro-inclusion activists of what they derided as “radical inclusion” or “forced inclusion” and organized protests to fight the extinction of special schools for children with disabilities.³³

MetaSocial Institute³⁴

In 1996, inclusive education in Brazil received a boost when two mothers of children with Down syndrome formed the MetaSocial Institute. Its focus is on inclusion and building strategies to change Brazil’s attitudes toward people with Down syndrome. Helena Werneck, an architect at the time, and Patricia Heiderich, a teacher, met by chance and found they had similar challenges: finding regular schools that would accept their daughters with Down syndrome and confronting the attitudes of the general public who looked at their daughters as if they were “aliens.” They felt that the best way to try to destigmatize the image of persons with Down syndrome would be through television, due to its reach to most of Brazilian society.

Werneck saw a TV ad that inspired her to focus an awareness campaign on Down syndrome. The ad showed two closed eyes, and when the eyes opened, a text read: “There is life after death—Donate your cornea.” She loved the message of the cornea donation campaign and set out to find the creator of the ad, Nizan Guanaes, one of the top advertising executives in Brazil, and asked him to help with MetaSocial Institute’s planned campaign to change attitudes toward Down syndrome.³⁵ Werneck and Heiderich met with Guanaes and convinced him to donate his time to produce a promotional ad that showed the capacity of persons with Down syndrome by featuring a man with Down syndrome playing the piano. Werneck and Heiderich were able to get this ad aired on prime time TV for free.³⁶

With the success of that TV spot, a second promotional ad followed in 1998; it showed two boys in a carousel, one with Down syndrome, the other not. The text said:

Carlos goes to school every day, his friend does not. Carlos goes to swimming lessons every day. His friend doesn’t. Carlos has piano lessons. His friend does not. Hey. This is

Carlos [image of the boy with Down syndrome]. And this is his friend [the other boy]. He is a beggar. Thousands of kids in Brazil need your help. Individuals with Down syndrome only need your respect. Down. Prejudgment is the worst syndrome.³⁷

This campaign won a Bronze Lion at the Cannes Advertising Festival in 1999, and the song “Fake Plastic Trees,” donated by Radiohead for the commercial, was so popular that it was re-released with a sticker saying it was the song of the commercial.³⁸

The MetaSocial Institute went on to work with the Brazilian media regarding the inclusion of persons with Down syndrome in a variety of program formats, from miniseries to entertainment programs to news stories. The advertising agency that created the MetaSocial ads always worked pro bono, but the Institute was treated as any other client—they explained to the agency what they liked and did not like. To fund the ads, the agency asked its business clients to donate one day of filming or towards other production costs. With a professionally created promotional ad in their hands, Werneck and Heiderich went to TV stations and asked them to air it for free.

With the success of the general awareness campaign, MetaSocial started a campaign in 2002 to encourage employment of persons with Down syndrome. Called “Waitress,” the ad is set in a busy restaurant where a young woman with Down syndrome is working as a server, delivering trays of food to several customers. When she is off-screen, the crash of a tray being dropped is heard. The ad then cuts to one of the non-disabled servers picking up what he had dropped. The tagline says, “You have just committed a mistake yourself. They can do much more than you imagine.”³⁹

In 2003, MetaSocial hired another ad agency, Giovanni FCB, to create a promotional ad around the theme, “It’s Normal to be Different.” In the ad, a 15-year-old girl with Down syndrome dances up and down the hall and in her bedroom, showing off many dance moves. At the end of the ad, it says, “It’s Normal to be Different.”⁴⁰ The teenager in the ad was Paula, Werneck’s daughter, who became the “face” of the campaign for many years. “It is easier to ask your own daughter to do a shoot for free, for many hours or in the middle of the night,” Werneck said.⁴¹ In 2005, Werneck and Heiderich decided to expand the campaign to cover not only other disabilities, but also other differences. “It was time to open up the umbrella,” Heiderich recalls.⁴² The campaign was called “Differences”⁴³ and featured people with tattoos, piercings, or out-of-the-ordinary hairdos and people who are bodybuilders, as well as a blind person with his guide dog, a wheelchair user and a teenage girl with Down syndrome.

Documentary: “From Grief to Struggle”

Another media event that brought more attention to Down syndrome in Brazil was a 2005 documentary about persons with Down syndrome. The filmmaker Evaldo Mocarzel, who also has a daughter with Down syndrome, is a friend of Werneck. The documentary, called *From Grief to Struggle*,⁴⁴ focused on the impact receiving the diagnosis of Down syndrome has on families, by highlighting the healing process for the family, the best ways to understand their child and the struggle to get their family member with Down syndrome included in society. The documentary, which received awards in a number of film festivals, featured Mocarzel’s daughter, Joana, who was 6 years old at the time. Werneck helped Mocarzel raise money to produce and promote the film. A copy of the documentary ended up in the hands of one of TV Globo’s main telenovela writers, Manoel Carlos, and he decided to explore the theme as a main plot in his telenovela, *Pages of Life*.⁴⁵

The *Pages of Life* production auditioned 15 children with Down syndrome,⁴⁶ and settled on 6-year-old Joana Mocarzel from the documentary to play the part of a child with Down

syndrome. Joana was the first main character with a disability ever to appear in a telenovela in Brazil. Joana and her family, who lived in Sao Paulo, temporarily moved to Rio, where *Pages of Life* was shot. The family members said that they were willing to make the sacrifice of moving for Joana's role because of the important visibility Down syndrome would receive by being depicted on a popular telenovela. TV Globo hired MetaSocial Institute co-founder Helena Werneck as an on-set coach for Joana. Werneck was always on set when Joana had to shoot a scene, which gave her significant access to the producers, directors, actors and writers, so she could emphasize the importance of the telenovela in changing the way the show's audience thought about persons with disabilities.⁴⁷

The *Pages of Life* Storyline about Down Syndrome

The storyline of *Pages of Life* that included the child with Down syndrome focused on the character of Nanda, who at 18 years of age gets pregnant. Her rich boyfriend, Leo, also very young, asks her to have an abortion, but she refuses. He leaves her. Nanda's mother, the antagonist Marta, becomes furious when she finds out Nanda is not only pregnant, but also expecting twins. When Nanda approaches delivery time, she has a terrible fight with her mother, leaves the house and is run over by a bus. In the hospital, Doctor Helena operates on Nanda and saves both infants, a boy and a girl, but the mother dies in the doctor's arms. The doctor contacts Marta to tell her that her daughter has died. When Marta goes to the hospital, the doctor tells her that Nanda's last wish was for the children to be named Francisco and Clara. Doctor Helena also tells Marta that Clara was born with Down syndrome.

This scene was written very carefully, in consultation with Dr. Zan Mustacchi, a Brazilian expert on Down syndrome, and Doctor Helena delivers the news in the most careful way possible.⁴⁸ The grandmother character Marta reacts terribly, and says that the child would be "retarded," a burden and that she will not take a "defective child" home. Marta decides to take only the boy and give the girl up for adoption, without telling her family.⁴⁹ Doctor Helena, who also had a daughter called Clara who died at 5 years of age with from meningitis, decides to adopt the infant with Down syndrome. Doctor Helena becomes a devoted and loving mother, and Clara grows up happy and healthy. Viewers see Clara's progress and use of speech therapy, physiotherapy, etc.

The show features Clara, aged 6 years, attending an inclusive preschool, and it is presented as an experience in which Helena has to learn to advocate for her daughter. When Helena discovers Clara is not participating or doing schoolwork because the preschool doesn't believe she is capable, Helena becomes angry, saying that the teacher is discriminating against Clara and that she will file a complaint in the Public Ministry (responsible for the rights of persons with disabilities in Brazil).⁵⁰ The NGO Escola de Gente (School of People) was a consultant for the parent-teacher meeting scene.⁵¹

Helena pulls Clara out of the preschool and begins to look for a genuinely inclusive placement. She visits many schools, and hears the same things parents with children with disabilities often hear—"we are not prepared," "she won't be happy here," etc. Helena even goes to a segregated special education school, but that school director says that it would be better for Clara if she went to a regular school. Finally, Helena finds a regular preschool that accepts Clara. In the usual coincidental plots of telenovelas, it is the same school that Francisco, her twin brother, attends and the children become friends. That leads to Leo, the twins' father, finding out that Clara is his daughter; he goes to court to ask for guardianship of Clara. Helena is devastated, but the judge decides that Clara should remain with Helena. The reunited twins become fast friends, and they and their parents become one big united family.

Exploding Myths about Down Syndrome

Disability advocates were pleased that many stereotypes and myths about Down syndrome were confronted by *Pages of Life*. Many in Brazil, as in other countries, believe incorrect information about the disability.

1. *Older women have babies with Down syndrome—false.* The probability of having a baby with Down syndrome rises after age 35, but more women who are younger than 35 have children with Down syndrome.⁵²
2. *It is not possible to have twins, one with Down syndrome and another without Down syndrome—false.* Cases of fraternal twins or triplets in which one child has Down syndrome and others do not are common, because these twins do not share DNA like identical twins. The Clara and Francisco characters in *Pages of Life* are not unusual.⁵³
3. *Segregated special education schools are better for students with disabilities—false.* Much research shows that children with disabilities learn better in mainstream environments, and inclusive schools are better for all students, disabled or not.⁵⁴
4. *Parents are sad to have a child with Down syndrome—false.* The birth of a child with a disability is primarily about adjustment; most parents do find it difficult to hear that their children have Down syndrome at first. However, research shows that parents and siblings love their family members with Down syndrome, just like any other person in their family.⁵⁵ In *Pages of Life*, Helena's life becomes much happier after adopting Clara. Clara's birth father, Leo, also shows his love for his daughter with Down syndrome, once he knows she exists. Although Brazilian society may have first viewed Clara as a "defective child," her character becomes one of the most beloved in the telenovela.

The Influence of *Pages of Life*

After its popularity in Brazil, *Pages of Life* was sold to many countries, including the United States, Canada, Chile, France, Mozambique, Venezuela, Italy, Israel, Cuba and Indonesia,⁵⁶ which led to more conversations about inclusive education in the countries that aired it. Disability organizations and advocates of inclusive education suddenly had popular culture on their side when discussing the topic. This meant the news media in these countries began paying attention to the subject of disabled children attending mainstream schools, especially those with Down syndrome. After seeing the telenovela storyline, parents of children with disabilities learned about their children's right to be included in regular schools and they started to demand it.

Research in 2007 illustrated that the Down syndrome storyline was one of the important issues discussed in the telenovela. Respondents who watched the episodes about Clara reported school inclusion as one of the most memorable issues addressed by *Pages of Life*: "the family relationship was the most frequently observed issue, followed by social inclusion, inclusion in school and health issues."⁵⁷

Teachers, parents and other people involved in the pro-school inclusion movement all agree that there was a "before" and an "after" *Pages of Life*.⁵⁸ Some argue that the show's writers should have made it clearer that it was a violation of disability rights laws in Brazil to refuse to enroll a child with disability at a regular school, but the writers do have the last say on the storylines.⁵⁹ However, according to the Ministry of Education school census, inclusion of students with disabilities in public schools in Brazil jumped from 13 percent of students with disabilities in 1998 to 93 percent in 2014,⁶⁰ and specialists say *Pages of Life* played an active role in this substantial increase.⁶¹ It truly did change Brazil's attitudes about people with Down syndrome and possibly many others with

disabilities. *Pages of Life* also helped raise the morale and self-esteem of people with Down syndrome in Brazil, and they saw themselves reflected in even more aspects of popular culture when the first dolls with the characteristics of Down syndrome arrived in Brazilian stores in 2007.⁶²

Pages of Life initiated a significant “social merchandising” trend in Brazil, and other characters with disabilities played by actors with and without disabilities were included in other telenovelas. In 2009, telenovela writer Manoel Carlos, who had introduced Down syndrome into *Pages of Life*, wrote for the telenovela *Live Life (Viver a Vida)*, in which a character who is a fashion model becomes quadriplegic. These episodes raised discussions about accessibility in Brazil. At the end of every episode, a disabled Brazilian appeared in a video, discussing his or her life. The plot involving quadriplegia was based on the life story of disability activist and journalist Flavia Cintra, who worked as a consultant for the storyline.⁶³ The disabled character, Luciana, a young woman, is the focus of happiness, not tragedy, in the telenovela. In the storyline, she gets married and has twins, mirroring the real-life Cintra, who also has twins. After *Live Life* went off the air, TV Globo hired Cintra, who became the first reporter with quadriplegia on Brazilian TV.⁶⁴

Media Representations and Disability Rights

At the same time a storyline about Down syndrome was airing on a Brazilian telenovela, the UN General Assembly was adopting the first human rights treaty of the third millennium, the Convention on the Rights of Persons with Disabilities (CRPD),⁶⁵ an international human rights treaty to protect the rights and dignity of persons with disabilities that, according to the United Nations had been ratified by 172 countries by March 2017.⁶⁶ Based on the Americans with Disabilities Act (ADA),⁶⁷ the CRPD is considered by the Special Rapporteur on Disability, Hissa Al Thani, to be a progressive step,⁶⁸ with its focus on fostering full participation of persons with disabilities in governments and the civil society.⁶⁹

The CRPD acknowledges the important contributions of mass media in changing how societies view people with disabilities. Article 8 of the Convention says media can be used to raise awareness about the inclusion of persons with disabilities. The Article states that countries should take measures that include “encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention.” Article 8 also recommends “promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.”⁷⁰

Research has also shown how crucial media are in educating a society about disability issues. In 2012, Haller noted that Western societies are “mass-mediated cultures, in which their citizens understand reality through personal experience and mass-media information,”⁷¹ so the presence of persons with disabilities in shows like *Pages of Life*, as well as films, news, advertisements and other forms of media, contribute to building awareness of disability rights for media consumers.

But people with disabilities themselves must be part of these efforts to create awareness through mass media. Clearly, *Pages of Life*’s storyline about Clara, a girl with Down syndrome, had much more impact because she was played by a child with Down syndrome. At a UN event in 2016, the author of this chapter explained that persons with disabilities should be brought into media spaces as educators. Using a personal perspective, they can present information to media workers on the rights of persons with disabilities, on violations of their rights, on the pervasiveness of stereotypes and on the need for accessible media platforms. “The inclusion of persons with disabilities as communicators in both public and private media organizations would benefit the realization of their rights.”⁷²

Efforts to include people with disabilities in all forms of media are finally happening worldwide, and many groups are monitoring these initiatives. For example, inclusive advertising, the incidental and inclusive representation of persons with disabilities in mass-reach advertising, has significant

potential to accelerate change in social attitudes towards disability and accordingly the realization of human rights. Some organizations, such as Starting with Julius in Australia and Changing the Face of Beauty in the United States, are having success by actively approaching companies to suggest that they should include persons with disabilities in their advertising. A number of Australian companies contacted by Starting with Julius are now using both children and adults with disabilities in their advertising. Some major retailers, such as Target and Kmart, have increased representation of persons with disability in their core marketing campaigns and messages.⁷³

In terms of monitoring television and film productions that have characters with disabilities, several non-profits in the United States have added that to their mission. For example, after a request from US disability advocates, the GLAAD organization that was annually reporting on LGBTQ characters on television, added disabled characters to its “Where Are We On TV” report in 2014.⁷⁴ A more in-depth review in 2016, the “Ruderman White Paper on the Employment of Actors with Disabilities in Television,” with exclusive focus on disability, found that more than 95 percent of characters with disabilities are played by non-disabled actors on television. The report also raised the problem of ongoing employment discrimination against persons with disabilities in the US television industry.⁷⁵ The University of Southern California’s Annenberg Inclusion Initiative added the disability category to its ongoing research into diversity in films, finding that characters with disabilities made up “only 2.4 percent of all speaking or named characters that were shown with a disability. Of the movies reviewed, 45 failed to depict even one speaking character with a disability.”⁷⁶

Some projects are actively working to train people with disabilities to work in news, entertainment and advertising media. In Australia, the Attitude Foundation focuses on employment and training persons with disabilities to work in the media.⁷⁷ In the United States, Los Angeles-based Down Syndrome in Arts and Media works as a casting liaison service for individuals with Down syndrome and other developmental disabilities like William’s syndrome, cerebral palsy and those on the autism spectrum.⁷⁸ Over 31 years, from 1986 to 2017, the New York City-based Alliance for Inclusion in the Arts actively advocated for full diversity as a key to the vitality and dynamism of American theatre, film and television.⁷⁹ It promoted authentic dialogue about race, culture and disability that embraced the complexity of underlying social and historical issues. In 2016, Lights! Camera! Access! 2.0 held mentoring and networking events for young people with disabilities interested in media careers in Washington, DC and New York City.⁸⁰

All these efforts, including *Pages of Life*, illustrate that the more people with disabilities are represented in mass media, the more likely it is that other people with disabilities will be hired for media work in the future. As important is the fact that societal attitudes about disability are changed when more people with disabilities are seen in the media, and the awareness that builds can actually lead to a more inclusive society. The *Pages of Life* storyline resulted in its Brazilian viewers learning more about Down syndrome than they knew before.⁸¹ That means many Brazilians suddenly had the information they needed to make positive changes in society for people with Down syndrome and other disabilities.

Notes

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