

CHAPTER FIVE: ANALYSIS

Photographing Disabilities: Three Photographers Talk about their Experience

Covering Down Syndrome Stories

When it comes to stories regarding people with disabilities, visual journalists often have an advantage because they are able to tell stories with visual proof, as the subjects' lives unfold in front of the readers' eyes. However, while these stories create a strong emotional appeal to the viewer, they may also make the subjects feel victimized. Therefore, one question that arises is how visual journalists cover those stories without victimizing the subjects.

People with disabilities do not want pity. They want to be considered part of society, where they are treated as human beings and contribute to it in their unique ways, according to a principle named normalization pioneered by Bengt Nirje and expanded by Wolf Wolfensberger in the late 1960s and 1970s. According to normalization, people with disabilities should be included in daily activities with their normal peers rather than being segregated. As a result, an approach to covering stories about people with disabilities was born. The journalistic approach tends to show the subjects as normal human beings while consciously de-emphasizing the disabilities. However, with this approach, the question arises as to how we can still honor journalistic standards if the main point of the story is the disability.

To seek answers to those questions, three photographers who have completed photo projects on subjects with Down syndrome - a well known disability - were interviewed. Amy Kontras made a story about Olive, the four-year-old daughter of Katie and Andy Werth, for her capstone class project at the University of Missouri. Taylor Baucom told the story of brothers Joc

and Champ Pederson at a Major League baseball camp. Hilary Camilleri, a commercial photographer in Waterloo, Canada, published multiple portrait series over a five year period for the Waterloo Regional Down Syndrome Society. The amount of time the photographers spent with their subjects was specifically chosen to reflect their time spent with the subjects, from just more than a week to the length of a camp session and, finally, a few years. In addition, the different approaches were also taken into consideration. Kontras followed the traditional observer model, while Baucom told her story from the subject's viewpoint and Camilleri did a survey approach with portrait series.

Previous exposure

The photographers were asked about their motivation to pursue the stories, and to my surprise, all three already had either direct or indirect exposure to people with disabilities and even Down syndrome.

Kontras' mother and aunt work as special education teachers, which exposed her to children with autism. "It's something I've kind of been exposed to my whole life, but not directly," she said.

Baucom, who actually has a sister with Down syndrome, said their relationship sparked her curiosity to get more involved in the Down syndrome community. "Since I grew up with a sister with Down syndrome, I'd always kind of stayed very tuned-in to the Down syndrome community, and my sister and I are very close," Baucom said.

Camilleri, on the other hand, was touched when she witnessed a friend having a baby named Caleb with Down syndrome. "I certainly knew what Down syndrome was, but I didn't have anyone in my close circles in my entire life that has Down syndrome. When I saw the

struggle and the challenges that they had when Caleb was born, and I saw how strong her resolve was, how strong her faith was and how badly she wanted Caleb to survive, it really touched me,” Camilleri said.

Based on the interview results, it turns out the photographers were not freshly exposed to the subjects of their work but had known about disabilities to a certain degree. This has both pros and cons: the photographers have a better understanding of their subjects, which in turn helps them get closer to their subjects and offers better access. However, at the same time, this might open the gate for a slight positive bias towards the subjects.

Process of the photographer’s work

The photographers were asked how they met the subjects, proposed the stories and persuaded them to grant permission. They were also asked how they proceeded to gather the materials to ensure that the dignity of their subject was respected and if there were any situations that made them consider abandoning their journalistic standards for the sake of respect to the subjects.

None of them experienced any major problems.

Kontras said the Werth family gave her good access. “When I met them, I let them know right off the bat - hey, I’m working on a project for class. I would love for you guys to leave your front door unlocked so I can come and go, like take pictures of you getting ready in the morning, be there when you’re brushing your teeth at night, just kind of let myself into your life.”

Baucom, on the other hand, took a first-person approach to adhere to her publication’s style, as the Player’s Tribune allows athletes to tell their own stories. “Because of the way we work with the athletes, some athletes write in their stories and send us their stuff, and then with

some, we hook them up with writers, and they're able to work with them and collaborate and tell a story together," she said. She then proceeded: "with Champ, I had seen his journals, and spoke with him, and recorded him, and transcribed him, and put it all together, and then sent it to him and was like, "what do you think? Did I get it right?" You know, I created a story out of it, and with the questions that Joc and him both got."

Camilleri, due to the large volume of subjects, decided to send questionnaires to find out the messages that parents of children with Down syndrome wanted to tell the rest of the world. "I always am listening to what messages they want to put out there. So yeah, each year that I work with the kids I kind of look to see what else we can highlight. I ask the parents, 'What kind of messages do you want to put out into the community?' and that kind of thing always helps," she said.

In addition, the trust between the photographer and the parents helped provide the access needed for a successful story, like in Kontras' case. "The Werth family was amazing," she said. "I photographed bath time with all off - those things when obviously they trusted me to use my judgment as a human being and not photograph anything lewd or publish anything that was revealing."

Camilleri added that patience is her key to success in working with children with Down syndrome. "You have to just make good eye contact and just be yourself around them. People pick up on positive energy and if you've got good energy around these children and adults, then they pick up on that," she said. She also said that since people have a range of emotions, there is no difference in approaching a child with Down syndrome versus a typically developed one.

In general, all three interviewees expressed that they gave the subjects the highest respect, which helped them gain the trust and accommodation to get closer and have a better understanding.

Reception of work

All interviewees expressed positive attitudes and hoped that their work would help raise awareness of people with Down syndrome.

Kontras mainly photographed sports before her encounter with Olive. The experience has changed her perspective. “I fell in love with Olive, I fell in love with the Werth family. I wanted to make stories about people in their emotions and not to toot my own horn, I think that I accomplished that well and I think that viewing my photographs, you really get a sense of who Olive is and what that family unit meant to each other and means to each other still.”

Baucom said covering stories about people with disabilities does not mean showing that they need help to live their lives. “It wasn't about helping or making him seem like, ‘Oh, isn't that nice that he's helping his special needs brother’, it's like, ‘oh, look at that. Two brothers that have two different backgrounds and two different ways of impacting people's lives’, she said.

“Champ, he's in the late twenties at the time. Seeing someone in their late twenties, speaking to the Dodgers organization and giving a speech before their playoff game, and being so accepted, I think that they'd have really positive thoughts and encouragement that right now there's a big future for people with Down syndrome.”

Due to her strong tie with an actual Down syndrome support group, Camilleri has a stronger voice. “People with Down syndrome typically were institutionalized decades ago. They

were written off as dumb. They couldn't do anything. Their life expectancies were very short. They were made fun of, they were segregated from society,” she said.

“The reason why I think this is so powerful is that we're fighting against some really old stereotypes, old nicknames like the old word "retarded," those kinds of things. There are lots of disabilities out there that don't have these traditional stereotypes around them, but people with Down syndrome really had stigmas around them for a very, very long time,” she continued.

“So what we're trying to do is break those stigmas down. It's a new day and age where we can, you know, help people with Down syndrome and support them in our communities along with everyone else that has a disability, whether it'll be visible or not,” she said.

Camilleri believes that making photographs of people with disabilities helps to raise society's awareness of underreported communities. “I think it provides a tremendous opportunity for us as photographers to create images that really evoke social change. [...] The photograph still holds a very powerful meaning to people. “

To sum up, all three photographers believe they had helped raise the awareness of society through their work, to show the human side of people with Down syndrome. They all embraced the normalization approach involuntarily, except in Camilleri's case when she intentionally aimed toward the goal of normalizing people with Down syndrome for her projects. This could have resulted from their previous direct or indirect exposure with people with disabilities for a long time, which might be a strong underlying influence that shaped their perspective.

Conclusion

The outcome of the interviews shows that photographers, when covering subjects with disabilities, tend to support the normalization of them, to show that they are just human beings

like their typically developed peers. It also comes down to the basic human-to-human interaction between the photographers and their subjects to make the work successful.

In addition, the long term exposure to people with Down syndrome also strengthens the belief that people are just humans and each of them is different.

The interviews provided considerable guidance to photographers who would want to cover stories about people with Down syndrome, as they outlined the thought processes of the interviewees and how they proceeded with their stories. Kontras' story showed that trust is the most important factor that helps open up access and show the intimacy between the subject and her direct family members. Baucom's approach showed a different, uncommon approach of storytelling that helped the subject tell his own story, therefore providing a truthful representation of himself. Camilleri teaches how to treat people with Down syndrome as human beings and how to engage them during the photo sessions.