

# INCLUDING SAMUEL

A Personal Story, In A New Medium

Dan Habib's first film focuses on the inclusion of his son, Samuel, in school, family, community – in everything they do. >>>

Photograph by Isaiah Habib

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**SAMUEL HABIB.** The subject of his father's 55-minute documentary film "Including Samuel," the journalist's youngest son has cerebral palsy. A strobing electroencephalogram at the Dartmouth Medical Center was used to measure problems in the electrical activity of Samuel's brain.

Story and Photographs by Dan Habib

CONCORD, NH

**T**HREE YEARS AGO, I SAT at my son Samuel's hospital bedside as he lay in a medically-induced coma. He was four years old and had developed pneumonia from complications following surgery. Samuel's neurologist encouraged me to be a photojournalist in the midst of my fear. "You should document this," he said.

That same year, I showed my documentary, *Teen Sexuality in a Culture of Confusion*, to a class of high school students. I created the video in 1995, using still photographs, interviews, and music. The teenagers liked it but said that without seeing the subjects move and talk, they had trouble relating to them.

These two moments pushed me in a new professional direction.

I began working on *Including Samuel*. The 55-minute documentary film will be released nationally this fall. Making this film helped me face my fears and biases head-on, both as a father and as a director. The film became my outlet for processing this new reality in our lives.

Samuel has cerebral palsy, which means his brain has trouble controlling his muscles. He uses a wheelchair and it is difficult for him to talk. *Including Samuel* is built on our family's efforts to include him in our school, our community, our family - in every aspect of our lives. Samuel's life is the central thread through the film, and I want viewers to learn a lot about him beyond the fact that he has a disability. He wrestles with his brother. He loves T-ball. He wants to be an astronaut when he grows up.



**THE FAMILY.** Dan Habib with his wife Betsy and their sons Isaiah, 10 (left), and Samuel, 7. Photograph by Sage Wheeler

But Samuel is only seven now, and including him will probably be more and more challenging as he gets older. So I also made this film to learn from the experiences of other people with disabilities, who can look back on the choices they made or their parents made and how these choices affected their lives. *Including Samuel* also documents the experiences of four other subjects: Keith Jones, Alana Malfy, Nathaniel Orellana, and Emily Huff. The film chronicles the impact inclusion has not only on them, but also their families, educators, other students, and their communities as a whole.

**ECHOES OF A PAST STORY.** *Including Samuel* really starts 20 years ago. As a newbie staff photographer with the *Concord Monitor*, I shot a story on Beaver Meadow Elementary School in Concord, one of the first elementary schools in New Hampshire to include kids with disabilities

# Five Lives Examined

Inclusion can be more challenging as children with disabilities grow older, so Habib documented not only Samuel's life but also four others, looking at the impact inclusion has on their families, educators, other students, and their community.



**KEITH JONES.** A leading Boston disability rights activist with cerebral palsy, Jones teaches hip-hop.

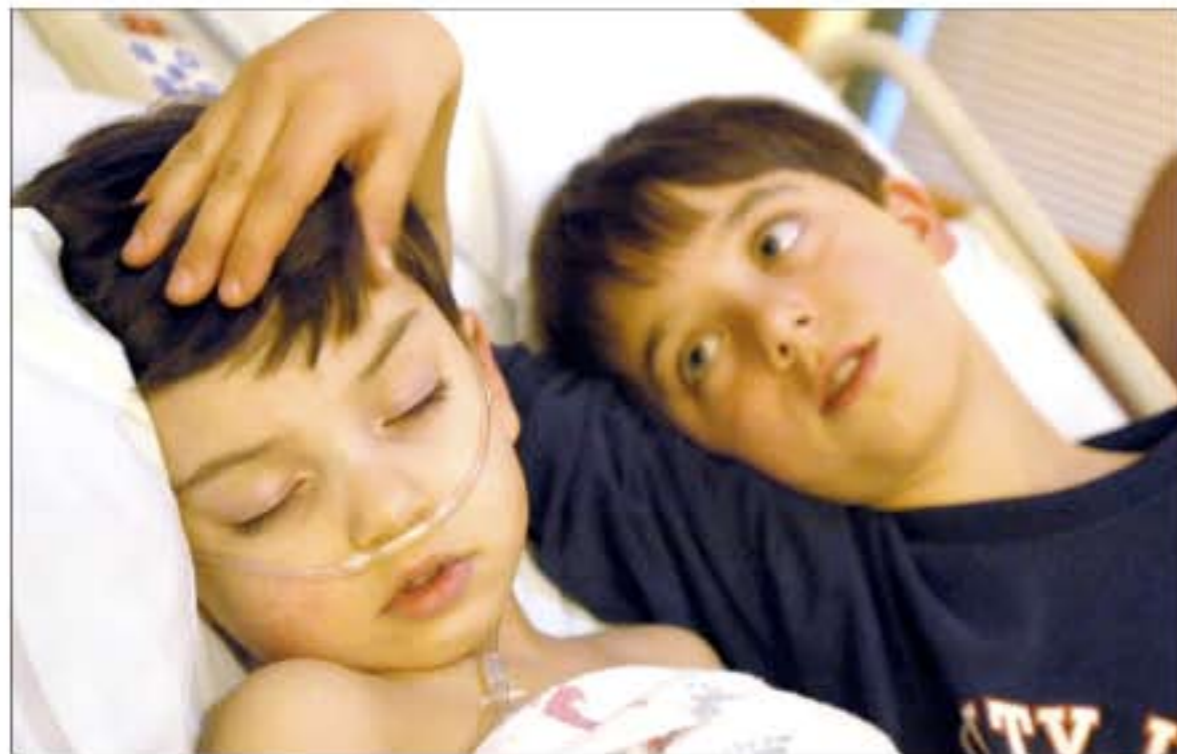
**ALANA MALFY.** She's part of a joint program that fully includes those with significant disabilities.

**NATHANIEL ORELLANA.** Autistic, he attends a Cambridge school that's a national model for inclusion.

**EMILY HUFF.** Modeling a cape she made that "gives me courage," she battles schizophrenia.



**READY FOR TAKEOFF.** Samuel sits on his father's lap behind the wheel of his grandfather's sea plane as they prepare for a flight.



**A BROTHER'S LOVE.** Three years ago Isaiah comforts Samuel in the intensive care unit of Mary Hitchcock Memorial Hospital. Samuel had been in a medically-induced coma during treatment for pneumonia after complications from a tonsillectomy.

in mainstream classes. Now Samuel is in second grade at Beaver Meadow, and I think about inclusion every day.

Having Samuel forced me to look at my own prejudice. When I saw people who couldn't walk or talk, what crept into my head? It's painful to admit, but I often saw them as less smart, less capable, and not worth getting to know. Is that how the world sees Samuel?

**THE LOGISTICS.** Okay, so I had all the motivation I needed to make a film. But how do I do it, given that I have no cinematography training, no film editing experience, a fulltime job, and the only video camera I own is an old Sony Handycam that I don't think works anymore?

The first step was to raise money. I knew from previous projects that the best chance to make this a success was to surround myself with talented people. And talented people usually don't work for free. The grants that exist for photojournalists are extremely competitive and have long lead times. I asked Granite State Independent Living, a non-profit that supports people with disabilities, to be my fiscal agent. That way, any funds given to the project would be tax deductible. Then, with the help of my wife (a professional fundraiser) I applied for grants to New Hampshire groups that care about the issue. I raised about \$15,000 in seed money. In two years I've raised about \$100,000.

My boss at the *Concord Monitor*, editor Mike Pride, approved my plan; I would take periodic unpaid sabbatical periods, sometimes a month, sometimes a week or a few days, to work on the film. I paid myself a salary out of my budget to cover these unpaid stretches. Staff photographers Lori Duff, Preston Gannaway, and Ken Williams have been incredibly supportive in taking over my photo editing responsibilities during my absences, which have

totaled about four months over the last three years.

My friend, photojournalist Meryl Levin, loaned me her Canon XLI mini-DV camera (I eventually bought my own). I love the camera, and the on-camera microphone is excellent. But this was three years ago; if you start a film now, I'd strongly recommend shooting on high-definition. I talked to some videography friends for basic shooting tips, but mostly it was trial and error and relying on my still photography instincts for composition, timing, and relating to the subjects. I learned the basic log-and-capture function of Final Cut Pro to catalog the footage.

Before I started shooting video, I had already taken many still photographs for the project, especially during Samuel's stay in the ICU and for a documentary story on Emily Huff, a young woman with schizophrenia. For both practical and aesthetic reasons, I decided to weave stills into the film along with the video. Plus, it was a lot more practical to always have a still camera with me to photograph Samuel than a bulky video camera. I often had trouble deciding whether to shoot stills or video while with a subject. I tended to err on the side of shooting video, especially if the ambient audio was interesting. But there were many days when I wrestled with the choice and missed moments as a result.

But the hardest decisions were more day to day with my family. When do I play filmmaker? When do I just play with my kids? I would block out chunks of time to film Samuel at school, and I tried to have the video and still cameras accessible at home without obsessing about missing moments. As the project developed, I could be more selective about when I picked up a camera. Sometimes the kids made it clear what they wanted. "Dad," Isaiah would say, "put down the camera and play baseball!"



**FULL INCLUSION.** When he was 3, Samuel sat in his supportive corner chair and smiled at a friend while attending a typical preschool in Concord, NH, where his parents are committed to full inclusion for Samuel in the community, family, and at school.

**FINDING A FILM** editor was next. My first call was to the office of filmmaker Ken Burns. I asked them to recommend the best freelance film editor in New England, and they named Rikk Despres of Pinehurst Pictures and Sound, who worked with Burns on *Baseball*. Rikk is an incredible film editor, and he also does all the audio and post-production work in his studio. Most of my budget goes to him, and he earns every penny. I travel to his Northampton, MA, studios once every month or two. But most of our work is done by eMailing scripts back and forth and reviewing edits together online.

Rikk and I cut a nine-minute preview of the film early in the process. The preview helped us plan the structure for the full film, and served as a tool for spreading the word about the project to potential funders and DVD distributors. I sent the preview to dozens of friends and colleagues for feedback. I've continued to share the rough cuts of the film with an expanding network of people, including a few documentary filmmakers, and the feedback I've received has been crucial to my decisions about the content and editing of the film going forward.

I don't have the time or the expertise to effectively promote the film. I applied for grants that would fund Web site development, a publicity firm, and a teaching guide. I hired our ace *Monitor* page designer, Vanessa Valdes, to design a logo, color scheme, and all the printed materials for the project. I contacted distributors of curriculum on diversity or disability studies to see if they would carry the film. Most distributors are happy to have nonexclusive rights, so in addition to selling the DVD through our Web site, I'll be distributing it through four national catalogs. Recently I hired a college film student to organize my database for e-newsletters and to submit *Including Samuel* to

film festivals (through Withoutabox.com, a must-use site for aspiring filmmakers).

If all goes as planned, I'll have the film done by early November. As I write, I'm getting ready to approach potential broadcasters like PBS and starting to arrange some limited theatrical screenings.

**GETTING TO KNOW INCLUSION, AND SAMUEL.** My hope is that the film will inspire the public, especially anyone connected to education, to talk about inclusion in a more informed and innovative way. And help them get to know Samuel at the same time. Making this film has helped me picture the full life I want and expect for Samuel. We have a supportive network of teachers, therapists, relatives, and friends who help us work toward that vision every day. And there is Samuel himself, whose smile and persistence make clear his own vision of happiness.

Samuel brought the disability rights movement into our home. And it came with a lot of questions. Can we continue to fully include Samuel as he goes to middle and high school? What about the times when illnesses force Samuel to miss weeks or months of school? As an adult, will he find love? Will he get a job that he likes?

I don't know the answers to those questions right now. But I know that Samuel loves life. He loves to laugh and he loves the Red Sox. He wants to keep up with his brother, and be a part of everything we do. He will teach a lot of people, which is good because the world has a lot to learn. ■

*Habib, who's been named New Hampshire Photographer of the Year six times, is the photography editor of the Concord Monitor. For information about the film and to sign up for updates, please see [www.includingsamuel.com](http://www.includingsamuel.com).*