



certain proof

Students with Disabilities Fight for Inclusion

Synopsis

Certain Proof is a feature documentary about three children living with significant communication and physical disabilities, who struggle against the public schools in an emotional battle to prove their worth.

Over the course of two and a half years, “Certain Proof” follows the lives of Kayla, Josh and Colin, three children with cerebral palsy. Despite multiple disabilities, they fight to prove that they are able to learn and deserve to be taught. Colin finds “No Child Left Behind” has exceptions; Kay combats harsh stereotypes inside middle school; and Josh faces continual doubt that he can learn at all. They and their families dare to hope in a striking testament to the complexity of the human spirit.

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Film Summary

Certain Proof: A Question of Worth reveals the stories of three young American children who face segregation daily, and particularly as their families seek to formally educate them in the public schools. Diagnosed as infants with cerebral palsy – an umbrella term for disorders to the motor control centers of the brain – communication for Josh, Kayla and Colin is often challenging and physically exhausting. No matter your cognitive ability or potential to learn, when you cannot speak or control your body in typical ways, it is nearly impossible to prove your intelligence or potential. For these students and their families, the seemingly insurmountable obstacle of proving their worth within the public schools is fraught with heartache, but also hope.

Josh

Josh, age 6, is confined to a wheelchair without speech and limited use of his hands. He uses non-verbal cues to hint at what he is thinking. Even though she has no proof, Dawn holds to the belief that her little boy is trying to communicate with a world that does not want to listen. She tirelessly advocates for Josh's education, but his public school is unclear what Josh understands or if he is capable of learning at all. The continual doubt renders his education little more than babysitting. Torn between fighting those that doubt her son and her own lingering questions of whether or not, 'he's really in there', Dawn seeks the proof she needs to help her son get the education he deserves.

An opportunity arises when a team of multi-disciplinary specialists invites Josh for a comprehensive assessment in order to determine his communicative potential. For Dawn, the thought of finally knowing if her son has real cognitive abilities is a mixed

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blessing. Either she'll be overjoyed or her biggest fears will be realized. Josh doesn't disappoint. Impressing each therapist with his skills, his mother finally gets the validation she's longed for and the okay to keep her dream alive of someday hearing Josh communicate, "I love you, Mom."

Colin

Imagine depending on a computer to say every idea you'd like to communicate. Now imagine you can't use your hands to type and each word has to be entered using a stick strapped to the center of your forehead. Meet Colin, a 10-year old boy with enough charm to make any girl smile with just a twinkle of his eye.

His communication device enabled him to progress through the first two years of school, but the faster pace of third grade challenges Colin's ability to keep up. Solving problems and answering questions takes an enormous amount of energy as he tries to control muscles that are fighting against him. His mother, Debra, desires to have her son taught alongside typical children, but that dream gradually slips away as he begins to spend more and more time out of the regular classroom and into one-on-one special instruction.

Since his physical disabilities aren't allowing Colin to prove his knowledge and comprehension in traditional ways, Deby feels the school's doubts are only setting Colin up to fail. Though the idea of inclusion is one that teachers and schools aspire to, the reality of teaching a child with severe disabilities in a typical classroom is beyond what most schools are prepared to handle. Both want what's best for Colin, but have different views on how to achieve it.

Kayla

Though she is able to speak, only those who know her well can understand. Cerebral palsy limits her mobility and communication skills, but not her spirit. A born leader, Kayla, along with her mother, Sandy, take on stereotypes at every corner they turn.

The next corner happens to be middle school. When Kayla's wheelchair rolls up to the doors of her new school, the teachers don't exactly meet her with open arms. Two of her teachers discuss their hesitation of having her in class and what affect it would have on the other students. How will Kayla be able to use a calculator or create a science project? Her classmates discuss their first assumptions upon meeting her and the unfortunate teasing that happens in middle school. Sandy readies herself for a long year of advocating for her child. Kayla readies herself for the same battle she's always had to fight... to prove herself.

We hear from Kayla directly as she discusses the challenges and judgments she faces at school. Luckily, she maintains a sense of humor. "Whenever I start a new school, they look like a bomb hit them!", she explains.

What the school soon finds is Kayla's smart. The students start to realize that she grades higher on tests than they do. We meet Jessica, Kayla's best friend, who sees

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behind her disability. From horseback riding to leading her science team, Kayla tackles each new challenge undaunted.

2 ½ years later

Although the assessment from the team of specialists years earlier showed Josh's ability to learn, Dawn shares that the school continues to have their doubts. They still have him doing shapes, colors and numbers. Things she knows he knows. For them the proof isn't there. Josh's work with a speech therapist outside the school system has yielded great results, though. He clearly has a "yes" and "no". In an interview with both Dawn and Josh, we see and hear Josh answer poignant and revealing questions about his feelings towards his mother and himself.

Colin's struggles have worsened. Overwhelmed by the workload, his move to middle school has left him depressed and frustrated. The school says legally they cannot adapt his work from grade level standards, so they place him on a separate education track without any chance of earning a high school diploma, a path Deby desperately fights against. For her this isn't how inclusion is supposed to work. At the young age of ten, Colin's future hangs in the balance.

Kayla has now moved into her first year of high school. There is an unending deluge of homework every night. Sandy tells the story of a horrible night of schoolwork that left Kayla in tears. Even though her mom tells her not to do another problem, Kayla wouldn't stop. For her, there is no rest in proving her worth to the world.

How much proof is enough? Karen Erickson, Director of The Center for Literacy and Disability Studies at the University of North Carolina says unfortunately children with disabilities are being held to a different standard than typical kids. "When we can figure out how to teach these children, we've figured very important things to teach all children who struggle. Every child has the ability to learn in some way and our job is to figure out what that way is."

The stories of these three children challenge us to rethink how we relate to and teach those living with disabilities.



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Director's Statement by Ray Ellis

My wife and I founded Footpath Pictures in 2002 dedicated to telling stories that reflect a social awareness on topics ranging from health and human need, peace and reconciliation, education and the environment. These types of stories easily get overlooked and can slip away before the world takes notice. We hope to be privileged to catch a few of those stories and present them in a way so the world pauses, just for a moment, and shares in what we've learned.

When we were introduced to a local non-profit dedicated to educating children with mobility and communication disabilities, our eyes were opened to an entire world we knew very little about. Receiving an appropriate education in the public school system is often difficult and frequently frustrating for children with multiple disabilities. Their responses take time and require lots of physical energy. The people around them often lack confidence in their interpretations of the children's responses. Constantly doubted on what they know, they have to have a different level of proof before they are taught the same as their non-disabled peers. Children who are able to learn and with strong cognitive abilities often are labeled, left behind, and underestimated.

Our purpose in producing this documentary is to lift the veil of disability, showing these unique and wonderful children in a truer light. All children, regardless of disabilities, are able to learn in some way and it's our job to figure out what that way is. We hope to dismantle dangerous assumptions and spur debate on better ways to individualize the public education system. Given the skills and education they deserve, these children can grow to become contributing and valuable members of their communities. Through the stories of Josh, Colin and Kay we see the potential these children hold not only for themselves, but for the benefit of society.

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Q & A with the Director

Who is answering the questions? What is your name/title and connection to the film?

My name is Ray Ellis and I am the Director and Co-Editor of this production.

We live in a world where communication is paramount, and if you cannot communicate, your worth to society is called into question. Our film, "Certain Proof: A Question of Worth" discovers that those who are physically unable to communicate, spend their lives trying to prove their ability to think and learn isn't necessarily as disabled as their outward physical appearance. Without 'certain proof' of their abilities, they are denied access to what most of us take for granted. The simple desire to be absolutely certain that these children understand us can have devastating affects on their futures.

Tell me about the children you followed for this film.

We followed three children in our film, Kay (13), Colin (9) and Josh (5). Both Kay and Colin suffered oxygen deprivation during labor and at four months old, Josh was diagnosed with a brain malformation. Kay is fortunate to have some speech, though she is only understood by those who know her well. That little bit of speech, takes her a long way and allows us to quickly appreciate just how smart she is. Colin is a bright-eyed ladies man - constantly flirting. He is a whiz at using his communication device with a head stick. Communication through his device though is tedious and tiring, and he sometimes stops using it because it's simply too difficult to motor through the

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system. Josh is a beautiful boy with a great sense of humor. Like most 5 year-old boys, he's really into spiders, bugs and Sponge Bob Squarepants. He speaks to his mother without any speech or device, only with his eyes or his full body (especially when something tickles him.) His mother sometimes questions if she's crazy or not thinking that he's really, 'in there'.

How did you choose them? What kind of barriers do they face?

Mainly, we were looking for kids who were challenged by both mobility and communication disabilities. We wanted to know why and when some kids “fell off the track” on their way to earning a high school diploma while others were able to make it through and move onto college. These kids face the same challenges that typical kids do but with the added hurdles of a physical disability. Imagine how frustrating it would be to find yourself a car you can't control on a highway where everyone else is going 60MPH. You are trying to get to the same destination and follow rules of the road, but you are trapped inside a vehicle that doesn't necessarily want to go there.

It seemed to us that the destination of a child with a disability is often set in the early years of their education. Where and how a child is taught during that period has profound affects on the child's future. We found three young children at different stages and at difficult transition points.

Josh was entering his first year of elementary school, Colin was entering third grade (when the expectations of students changes dramatically from the early elementary years) and Kay was entering middle school, which, let's face it, was difficult for all of us! At every transition they face teachers and students who simply cannot figure out how to handle a severely disabled child in a wheelchair. Unfortunately, the typical response is to assume they cannot survive in a class of their peers and to send them on to Special Ed where the expectations for students are set far lower.

What gave you the idea for this film?

Our production company, Footpath Pictures, works with a number of non-profits and we were commissioned by the New Voices Foundation to produce a separate project featuring these children and their families. Though they were trying to raise money to support their goal of building a center that would help these children in the public schools, we realized there was a far greater problem - no one really knows who these children are. The majority are isolated in Special Ed classrooms and do not interact with typical kids. We were inspired by the journeys of these children and their mothers and we wanted to bring their story to the rest of the world. These children are among the least understood in our schools and in our society.

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What did you learn by making this film?

Wow, I learned a lot about my perception of communication. Susan, the Producer and Story Editor, and I set out to tell this story from the child's perspective. We had a vision of sitting down and interviewing each child as we would anyone else. That seems completely naive now. We believed that they could simply pre-program their little devices with the answers to our questions as long as we sent them a list prior to shooting. Though we knew the machine could never represent the emotion behind their words, we would at least get words that an audience could understand. Very early on though, we realized how physically challenging it would be for these children to communicate even a single word. Pulling the answers out of these kids was not going to work. It was then that we started to understand the difficult task of teaching children who are not able to efficiently communicate in ways that we are comfortable with.

Susan and I are married and right after we finished shooting the first part of the story, we had our first child. Watching our son slowly figure out how to speak, one sound, then one syllable, then one word at a time in that first year gave me a greater appreciation for how physically demanding speaking actually is while we are learning to use our bodies. It also reminded me of how much we communicate before we even speak a single word. Most importantly, I didn't ask him to prove that he could think or learn, like any parent, I simply assumed he was brilliant and treated him that way. That luxury is not what these kids are experiencing outside of their own homes.

What do you hope audience members walk away thinking/saying/feeling?

We really want the audience to walk away with a better understanding of these children and their families, the struggles they go through in obtaining a proper education, and to also dispel some old assumptions. We'd like to start a dialogue about education and how we can best implement change so all children are taught in ways that enable them to reach their true potential. These three kids couldn't possibly represent all children with CP or all children with a communication disability, but their experiences remind us of the humanity of anyone hidden by the mask of disability. It's not an easy story, but it is a necessary story if we want things to change.

Our film doesn't wrap things up in a tiny bow with all the answers. There are no simple solutions. We hope that the audience leaves considering how much their own assumptions alter the way they perceive people with disabilities.

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Why did you follow them for 2.5 years? And what did that lend to the film?

We didn't initially plan on following the families for two and a half years. Our first production schedule called for six months of production. The economy and lack of funding kept us from finishing it as quickly as we wanted to. Over that time we got to know the mothers much better. A couple of years later when we showed them a cut of the film, their responses were much more raw, less careful about what they said, less PC. The seeds that we saw planted in the early years for these kids were playing out in unexpected ways as they grew older. Each child had grown so much and faced new hurdles to their education. We knew we had to go back and revisit their lives. I think they let their guard down because for at least two of the mothers, the future felt firmly out of their hands. Because the story now covers two and a half years, it's much more interesting and drives home why it is essential to not miss any opportunity to teach by getting stuck in the rut of looking for measurable proof.

Is there anything else I'm not asking that I should know?

Since we've completed the film, posted the trailer on YouTube and created a Facebook page, the interest and response has been overwhelming. If you visit the "Certain Proof" Facebook page, you'll get a sense of the families who are desperate for their stories to be heard. In truth, you can count on one hand the number of films that represent this community so there is a real sense of validation and excitement in this film being out there. We're so grateful, "Certain Proof" is an official selection of Dances With Films in West Hollywood. The screening is June 4th at 10:00am at the Sunset 5 Theater located at 8000 West Sunset Boulevard. It also screens the same day in Seattle at the Seattle True Independent Film Festival. I hope people have a chance to step into the shoes of these children by coming to see this important film. There are thousands of families out there hoping that this film and the stories of Josh, Colin and Kay can truly make a difference.

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