

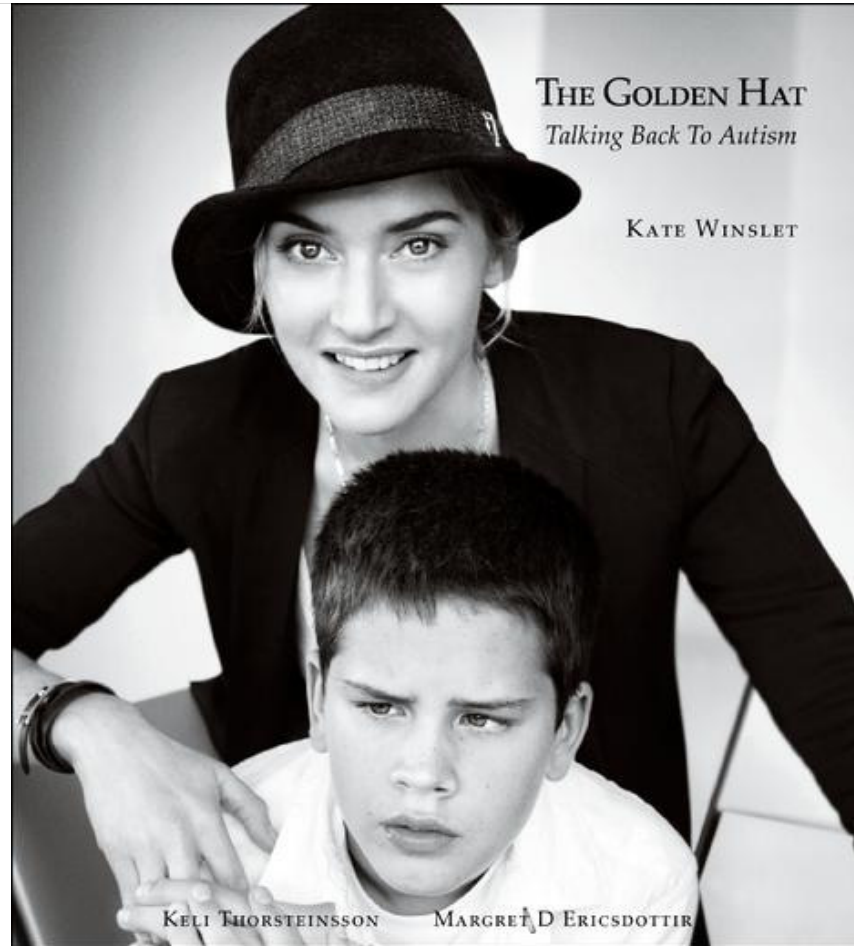
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The Write Place At the Write Time Book Review- Hot off the Presses



Cover Image of The Golden Hat: Talking Back to Autism

**The Write Place At the Write Time Book Review Presents:
The Golden Hat: Talking Back to Autism by Kate Winslet,
Margret Ericsson and Keli Thorsteinsson**

Review by Denise Bouchard~

The King

By Keli Thorsteinsson

*There was a king in a big country
He grew up on a tree
Because he was brought up by birds
He sang like birds
And he tried to tweet like them
One day he was spotted by a man
He was singing on a branch of a tree
He was brought down and given education
It was hard work for many years
When he grew big he became clever man
And great soldier
Slowly he grew to be a king
END*

~From THE GOLDEN HAT by Kate Winslet with Margret Ericsdottir and Keli Thorsteinsson. © 2012 by the Golden Hat Foundation.

The poem above was written by a young boy with severe non-verbal autism who was locked inside of himself for ten years. What it took to make this deeply metaphorical work of art possible for him and other children like him, is behind the amazing odyssey of *The Golden Hat: Talking Back to Autism* by Kate Winslet in conjunction with Margret Ericsdottir and her son, Keli Thorsteinsson.

Recently, I became aware of The Golden Hat Foundation on *Live! with Kelly*. What piqued my interest the morning that I saw actress Kate Winslet recounting her beginning ideas for The

Golden Hat project was the serendipitous way that the initial notion of it came to her.

Kate had provided the English-language narration for a personal documentary which chronicles one woman's (Margret Ericsdottir's) journey with her autistic son, Keli, through the quagmire of diagnosis and oftentimes despair to hope and finally a word seldom heard of in the world of autism- breakthrough.

After meeting with Margret and then becoming friends with her, Kate and Margret corresponded through a series of e-mails about Keli's progress. Kate had the feeling, after meeting Margret and Keli, that "she could not just walk away", so she asked Margret if there was anything more she could do and the dynamic Margret replied, "Raise awareness."

Soon after, an idea came to Kate as she was brushing her teeth one morning: "It involves a hat," she related to Margret in an e-mail, "and a lot of very famous people." Kate's idea was to use a hat as a common symbol encouraging communication and have celebrities take a self-portrait accompanied by a quote concerning something that was important to them. Margret was floored not only because Kate was going to be helping her in a way that could make such a profound difference, but also because Keli had just written a poem the night before called "The Golden Hat" about an autistic boy who could not speak and had a golden hat that could talk for him, expressing his thoughts and feelings. This powerful pairing between these two women for the cause of autism was clearly meant to be. It is this kind of synchronicity that gives me chills; I had to know more. My degree is in Early Childhood Education and I'd seen severe autism firsthand in my coursework and believe me, with their sensory overload, these dear children were not writing poetry but in some cases, were actually banging their helmet-guarded heads against the wall throughout the day. They could not communicate with the world around them and for ten long years, neither could Keli. Margret was told that Keli probably only had the intelligence of a two-year-old and institutionalization was suggested. She diligently worked

with her son each day, yet there were no breakthroughs, no knowing what her son needed or thought about, or if he had any particular preferences on anything at all.

Just imagine for a moment not being able to communicate with your child. I remember when my daughter was a few months old and she came down with a virus that quickly left her listless. When her doctor wanted to hospitalize her because of dehydration, I had such a degree of anxiety over her welfare. The illness was short-lived but that state of not knowing what was wrong initially, even for a short while, made me feel beyond frightened, beyond helpless. Thinking of that instance before she was old enough to communicate, helps me to understand even a small portion of the overwhelming challenges that these parents face every single day.

Though this was to be simply a review of *The Golden Hat*, I will be including references to the documentary, *A Mother's Courage (aka The Sunshine Boy)*, followed by interviews with Margret, Keli and the amazing Soma Mukhopadhyay who introduced the extraordinary Rapid Prompt Method and letter board to Keli which were behind his first communication at the age of ten. I do this in order to provide the reader with a full scope of what I feel is amazing progress for a diagnosis that in the past might have meant institutionalization, let alone being given the right environment in which these children can receive a tailor-made education and learn to communicate. Also, we are shown by the children themselves how we can listen to their very unique and profound words which are no longer locked inside and may well change the world for the better.

How it All Began...

A fiery-haired woman with large blue eyes looking very strong and determined is clutching the hand of her young son who walks with great difficulty beside her over the rough terrain on the hillsides of Iceland, a place that looks to the casual observer to be a very cold yet strangely beautiful, almost mythical place. The

skies overhead look ominous, white lightning flashes continuously, streaking through the gray sky and white matter of the clouds much like the quickly firing neurons in the circuitry of the brains of individuals with autism. This is how we first meet Keli and his fiercely loving mother Margret in the documentary. Right away you are taken in by them.

Initially, Margret simply wanted to make a "cute" documentary showcasing autism but then it evolved on its own and in her own words, "...became so much bigger than I had initially planned." The wonderful thing was not so much that the documentary was successful, but that she would finally reach her son and get to know this beautiful little boy and what was in his heart for the first time. She also shows us the impact that these incredible individuals, once they are able to express themselves, can make.

I loved the fact that we got to hear from author and consultant, Temple Grandin who has a high-functioning form of autism. She has shown us how she is influencing the world and teaching us so much today because her brain is so different. She remarked, "I wish everybody would work together to get constructive things done in the world."

Margret's mission in making the documentary was to achieve three objectives: 1) Raise general awareness; 2) To represent the entire autism spectrum and to show how varied the condition can be; 3) To shed light on the many existing opportunities and possibilities in the treatment of autism, making it possible for people with autism to take an active part in our society.

It was Margret's intention to start a foundation because "...they are getting older, as well as we the parents. Our dream in the beginning is to create campuses for those with autism where they can live and work with the social assistance everyone needs, as intelligent human beings."

Margret's research and determination led her to the Halo Center in Austin, Texas run by Soma Mukhopadhyay. I was amazed by Soma and her way with the children but most impressed by the

effectiveness of her methods. I was also deeply moved by the children themselves, their progress, what was in their hearts and most of all by their sense of humor. The world needs these children just the way they are; they are brilliant, unique, special people who will each leave their own mark.

The Book

I AM REAL. These were Keli's first words at the age of ten. His mother relates, "I suddenly realized that Keli had been listening to us the whole time and he could understand everything that was going on around him." Because the doctors believed him to have the intelligence of a two-year-old, his parents had been reading him books about *Teletubbies* but the doctors were very wrong as his mother can attest; Keli is very opinionated and he prefers the *Lord of the Rings* series and his favorite restaurant is a sushi bar. He can now tell his mom where it hurts, and it hurts terribly, for Keli, sadly, has been found to have osteoporosis-though it doesn't stop him from wanting to try bowling.

The celebrities in the book make you want to stand up and cheer for their caring and compassion and I must add- very cool photos - all artistically unique self-portraits. The quotes were often with the question in mind of what your first words would be if this was the first time you were able to communicate. Penelope Cruz offers words that are akin to the beginning of a journey to break down communication walls: "Thank you for listening. Thank you for believing. This is just the beginning..."

Interviews

Below are the interviews. The first set of questions are with Margret Ericsson, producer of the documentary, co-author of the book and mother of Keli. The second is with Keli himself, now fourteen, handsome and thriving. The third is with Soma Mukhopadhyay, the teacher who developed the Rapid Prompting Method and owns the Halo Center in Austin, Texas.

Questions for Margret:

1) Keli is a beautiful child with such a wise and joyful spirit. Describe for us how you and your husband felt when Keli expressed the words "I am real". This is an incredibly profound statement. How does it feel to finally know what's in your son's heart?

Thank you, Denise, you are so correct. Keli has such a wise and joyful spirit, he is such a great blessing and joy to all of us around him. I do not think that any words are powerful enough or descriptive enough to convey the feelings I felt when Keli first communicated by pointing on a letter board, "I am real". As I wrote in our book, The Golden Hat, it was like a new beginning - a new opening between a mother and her son. Finally my youngest son, Keli, who is totally nonverbal, has a way to communicate!

I have always felt so close to my son, Keli, but I truly first met him when he started to communicate by pointing on a letter board at the age of ten. It feels glorious being able to "talk" with my son - getting to know him better each and every day. Each time when he communicates it is like unwrapping a precious gift. What really surprises me is how opinionated he is. He has a strong will and really knows what he wants - which is a good thing!

2) Is the HALO Center in Austin, TX, "which is academic instruction leading towards communication for persons with autism" the only place in the world using this type of method? I think this is such a revolutionary breakthrough for autism; how well known is this method elsewhere?

At the Golden Hat Foundation we recommend any method that treats those with autism as intellectually capable. The key is that we give these children an effective means to communicate and then teach them academics, not just life

skills such as folding clothes or brushing their teeth. In this way they can become an essential part of our society.

I would be remiss if I didn't mention how the iPad has revolutionized the world for those with nonverbal children, making it easier than ever to communicate.

3) When back at home in Iceland with Keli, how did you continue his communication and learning process? It seems that you've done such a wonderful job with him that we'd like readers whose families are affected by autism, to know some things that they can do at home for their loved ones.

We were lucky in the sense that Keli comes from a dual language family so he is used to two languages, both, Icelandic and English. I train Keli every morning for 30 minutes giving him a short lesson and allowing him to answer questions on his letter board. His dad, Thor, works with him on the Big Keys keyboard each morning as well. This keyboard has large sized keys, helping Keli since he does not have good fine motor skills. Slowly and gradually we are trying to get him ready for communication on a computer.

Like every parent of a child with autism knows, it is a lot of hard work and dedication each and every day. However, this time it feels different because we actually know he is progressing, since now Keli is able to communicate. He now has a say in how things are run at home, what he likes and what he does not like, etc.

4) Your husband has been described by you as your soul-mate and indeed he must be as your relationship, clearly, is a testimony of true love. Your two other sons are amazing with Keli. You've done such a great job keeping the family life balanced for everyone. For the other families who may, as mentioned in the documentary, be having difficulties staying together due to pressures and time constraints, can you give some words of advice?

Thank you Denise, what a wonderful compliment!

All I can say is hold on, it is going to be a long and challenging ride, but you can do it together, strong and determined, for the love of your children. When we can conquer the challenges we are given in life - and many times they seem too big and difficult to handle - then we will harvest the sweet victories all together with joy and pride in our hearts.

5) Do you think it's possible, through research, funding and awareness, that there could ever be a cure or prevention?

I definitely think that much more funding is needed for research of the "forgotten half" of the autism spectrum. Approximately 50% of those with autism have nonfunctional speech and are considered to have "severe" autism. These individuals have been overlooked and rarely studied because they are - for the most part unable to communicate - which makes them much more difficult to research. Studies are badly needed as there are millions who could benefit from possible solutions to their autism.

But we also need to acknowledge the growing population of individuals with autism that are here right now. We need to emphasize early intervention - which is crucial for their success - and address the situation as it is. We should not overlook the aging population of individuals with autism. They will outlive their parents. We need to develop appropriate living campuses, provide career training, and give them ample opportunities for social interaction and recreation.

Questions for Keli:

1) I see you and just how real you are. We are so lucky to have you in the world right now to teach all of us about autism. I love

your poetry and want to know if there is anything you'd like to say to our readers about the documentary your wonderful mom made with you.

Keli and mom are great team. I love mom. She has always believed in me and then made others believe in me. We wanted to educate people about autism.

2) How has your life changed since you went to the HALO center?

Keli can now speak his voice by communicating on a letter-board and now I am getting academic education.

Soma is a petite Indian woman with a firm but loving way of interacting with the children. She "developed the Rapid Prompting Method to teach her own son, Tito, who is a published writer despite his autism." She's extremely modest, saying that her methods are not dramatic but I feel that after having seen the documentary, the results speak for themselves.

"There is no justifiable excuse for depriving a group of individuals of exposure to knowledge and an academic education simply because of their uneven cognitive development and impaired sensory motor function"- Soma Mukhopadhyay

Questions for Soma:

1) The commonly held belief of leading scientific researchers as shown in a recent *USA Today* article, is that the only effective alternatives for autistic patients are behavioral treatments "... which depending on the state and one's health plan, may not be covered by insurance. They are very intensive... and horrifyingly expensive." Having seen the documentary, it is readily apparent that you are teaching these children and getting through so that even a nonverbal child who has never been able to communicate to their parents is now able to express themselves. How would you give hope about how the HALO Center is different and reaches beyond a child's behavior? How is it that the Rapid

Prompting Method is not yet widely known when it appears to be producing dramatic results? For families who cannot readily afford an intensive program, how easy/effectual is RPM to use at home?

I think every approach is aimed towards behavior modification, trying to 'fix' things. My approach is different. I do not want to turn a square into a triangle. But I want to grow the potentials of a square. Education is one way I can introduce an autistic person to the world that is bigger than behavior. I do not know about the 'dramatic results' but we are very small as an organization and want to remain small so that we can keep the quality of our work. HALO is more like a family to those who are involved with it, so we are not interested in growing ourselves because 'a small family is a happy family ;)' and the happier we are, the better energy we can put into our work. We want to empower families to work with their children more than professional intervention. If a child and a parent can communicate and learn from each other, who needs expensive treatments?

2) What do you think of the research going on right now that involves creating brain cells in a lab dish by transforming skin cells of autistic children into stem cells, then back into neurons or brain cells as well as drug therapies?

I keep myself much less involved or informed with autism research, so I may not be the right person to answer it. I just see an individual ready to learn whatever be the label.

3) How did you begin developing this treatment for your son, Tito?

Tito is my textbook. When I started to teach Tito I first had to learn who Tito is. And that is how my work began. It is a long story and Tito wrote some of it in his book. I haven't finished reading my textbook yet. I am reading more and just doing my worksheet pages.

4) When Keli Thorsteinsson came to you, how did you tailor the program to his needs?

Like anyone. Every student is unique. All I needed to do was to find his open learning channels and try to introduce him to (a) education (b) work on his skills to use his hands, fingers to spell so that he can show what he learned. It isn't difficult at all when we look at our students beyond behaviors.

Here I take the opportunity to speak to the children of the impression that they left me with from both the book and the documentary:

Breaking Through

*I put on this hat,
it has magical powers*

*With it I can go to all sorts of interesting places
And while away the hours*

*But I have had a chance of late
For a glimpse into your hearts
Revealing to me your brilliant spirits and your beautiful, open
souls*

*And it has been more inspiring to me
than all the world's riches,
gems, silver, and gold*

Links:

<http://www.goldenhatfoundation.org/>

[http://www.halo-soma.org/main.php?
sess_id=e0c7cd245f04de6327701daa3c668672](http://www.halo-soma.org/main.php?sess_id=e0c7cd245f04de6327701daa3c668672)

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