

## My Daughter - My Inspiration!

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### The Journey Begins from Pakistan

Sophia, our first and only child, was born in 2005 in Pakistan. When she was brought to me and I held her, I noticed almost instantly that something was different about her right hand and fingers. Upon asking the nursing staff what was wrong, I was told, "It is Allah's will," without further explanation. Upon handing the baby over to my husband, the nurse informed him of a malformation in the baby's bones and told us that she should be taken to a pediatric specialist within a couple of weeks.

Upon medical examination, it was revealed that Sophia was born with serious bone deformities in her right hand and leg. Although her condition was not life-threatening and was treatable, this news was a blow to me, personally. No matter how much I tried to console myself, feelings of guilt and shame kept drowning me. It was supposed to be a joyous occasion in our lives, as Sophia was the first grandchild for both my husband's family and mine. However, I felt guilty and somehow responsible for what was happening to Sophia. It was as if I had done something wrong and caused this deformity.

The first thing I noticed was the negative attitudes of various people from both of our families after we brought Sophia home. On both sides, family members responded with traditional and superstitious judgments. For example, my mother mentioned a dream where she saw me giving her a bowl of marbles, but some marbles were missing. She believed the missing marbles were a metaphor for Sophia's missing fingers. Similarly, my mother-in-law mentioned that she had lost a piece of my husband's clothing on the day of the wedding, a warning that something would go wrong in our marriage. At one point, my sister-in-law asked me to cover Sophia up with a blanket, so that people who came to visit and congratulate us would not see her deformity. Aunties kept asking me if I had accidentally slept on my stomach during pregnancy. Did I use a knife during the moon eclipse? Did I take any unadvised medicine? Some even went to the extent of shamelessly asking me if I had had sex during the last trimester of my pregnancy.

This was very difficult for me, and I could not help but wonder what the big deal was about a missing bone. What was so odd or so wrong about having four fingers instead of five? Going through post-natal depression, staying up all night trying to feed the baby, answering questions about what went wrong and how it happened—it all took a toll on me. It seemed to me as if the celebration of motherhood had turned into a curse and I was its victim.

### **Next Stop: London**

Amidst the questions and stress, we eventually decided to take Sophia to England for medical treatment. We moved to London when she was only one year old. We wanted the best for our child: She was lucky enough to spend the foundational years of her life in a society where children with physical impairments are more readily accepted, and where cultural practices are far less demanding than in Pakistan.

### **Saving Grace: ACES**

During this time of sheer desperation and hopelessness came a ray of light when I was directed to a local charity called ACES. This was a parent-child self-help group supporting families with young children with disabilities. I started attending sessions at the organization twice a week; this gave me a chance to meet other people in a similar situation. Although my daughter's condition was much less severe than some of the children there, the ability to speak with people who were experiencing something similar helped me a great deal. The more I became involved with ACES, the more I realized that I was not the only one going through a difficult time. The more I spoke with parents, the more I learned about day-to-day issues that arise when supporting a child living with a disability. Slowly, I noticed a shift in my perception toward disability. I started to see it as more of a natural occurrence than a catastrophe. It was at ACES that I realized my potential and my strengths.

### **My Growing Aspirations and a Research Study**

While at ACES, I was approached by a researcher who was studying the support needs of Pakistani families with children with disabilities and additional needs. I became actively engaged in this study as a participant and I worked with the lead researcher. This was a turning point in my life, as later, this research would become the starting point of my very own research study. I met

several other Pakistani families who had faced similar problems to my own, such as housing issues, low-income levels, stress, and negative attitudes from the community regarding disabilities. The researcher held interviews and organized focus group discussions for Pakistani families. Her research techniques incorporated creative methods and encouraged the participation of all family members. This research transformed my understanding of disability and challenged my ideas and thought processes.

We eventually presented this study at an international conference in London, which opened up many ventures for me. I was approached by a UK-based researcher at the conference to hold and facilitate sessions for Pakistani families with children with disabilities.

### **One Step Further: Higher Education**

As time passed, Sophia underwent several corrective surgeries and began to gain independence. She grew up to be a lovely child but continued to feel the negative attitudes from the surrounding South Asian community. She still faced sneering looks and abrupt comments about her fingers. People asked her questions that she found difficult to answer at such a young age. Many women from the Pakistani community worried about her marriage prospects, which ultimately prompted me to study the gender and educational experiences of Pakistani special needs children and their families in greater depth. My experiences participating in and supporting a research study, coupled with my personal situation, spurred me to dig deeper. I decided to enroll in a master's degree in Education, Gender, and International Development at the University College of London Institute of Education. Enrolling in this degree was one of the best decisions I have ever made in my life. It opened a whole new world for me and enabled me to look at gender and disability from a completely different perspective.

Learning about disability through the lens of gender really challenged my fundamental understanding of disability. I noted these gradual changes in the ways that I started acknowledging that my daughter was flourishing and that she felt she was fully accepted for who she was. It did not make a difference to me anymore if Sophia had missing bones in her body. My longstanding feelings of guilt were beginning to be dissolved by a strong sense of empowerment. I found myself more comfortable in dealing with people and answering their questions about her condition. I realized that "being different" did not necessarily mean being unable to maintain an equal position

in society. This significant transformation in my attitude had a direct impact on Sophia, and I watched her consequently gain confidence when dealing with questions from those around her. This was evident by the fact that within a few months, she could not wait to “show off the scars” from her surgeries to everybody we met, and to brag about her bravery during the operations. There was a very visible change in both of us as we had reinvented ourselves from shy and easily intimidated people to confident and bold individuals who took pride in the fact that being different meant being noticeable!

Juggling childcare, a job, and full-time graduate studies was not an easy task and was only made possible by the unconditional support my husband gave me and Sophia throughout my years of studying. Contrary to cultural and gender norms, he cooked for us while I attended lectures; he stayed in the hospital with our daughter while I worked on my assignments; and he took time off from work to be with Sophia while I flew to Paris for a study tour. In the truest spirit of equal companionship, he successfully managed to balance my need for space to develop and grow, without compromising our religious and cultural background.

### **The Way Forward**

My daughter is thirteen years old now. She has blossomed into a wonderful young lady and has high aspirations for her future. It has been a long road for all of us and thankfully, her medical treatment has now finished. Along the journey, we have made sure to give her every opportunity that we could afford, to give her unconditional love, and to impart strong values in her heart and mind. She enjoys a good life, and positive energy flows around her. She has inspired me to take on greater challenges in life and to channel my desperation into hope. I have built a successful career for myself working in the Equalities and Diversity team of a top university in London. I also work on several projects about inclusive education, training parents, and family relationships. My parenthood experiences drove me to set up a support network for other parents and caregivers. Every day I think about what an amazing person my daughter is and how much strength she carries in herself. Our secret is resilience and hope. The way forward is to transform the negative energy into positive energy, as God helps those who help themselves. As commonly believed and practiced by Muslims all over the world, “When Allah closes one door, He opens many others.”

### *My Little Rainbow*

You're so sweet  
My darling Sophia  
We love you oh so dear  
You are the rainbow in our sky!

I wrote this poem in honor of Sophia, because  
to me, Sophia is a rainbow:

- Full of colors
- Stretching across the sky (across our lives)
- Beautifying our lives

