



From The Statistician's Point of View

by Stephanie Kieszak-Holloway

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"Correlation does not imply causality." When I was an undergraduate student in statistics, that phrase was drummed into my head. Simply put, it means that two things can be related without one causing the other. For example, having blonde hair is correlated with having blue eyes, but one would not say that there is a cause and effect relationship between the two. It is possible that instead, they are both caused by a third event. Blonde hair and blue eyes are linked because the genes responsible for hair and eye color occur close together on the same chromosome. Throughout my undergraduate and graduate training and thirteen years as a biostatistician at the CDC, I continued to hold onto this truth. However, when my daughter, Kendra, was born seven years ago, the phrase took on a much more personal meaning.

Kendra was born blind. The merry-go-round of therapists and doctor appointments began immediately and I had no idea a tiny baby required so many therapists. I was told that babies who are blind are automatically delayed in reaching milestones and not to expect Kendra to walk until she was two or three. At first I found comfort in those predictions. If my daughter didn't reach a developmental milestone at the same age as most children, there was a ready explanation – it was all because she was blind. However, my sense of comfort faded quickly to be replaced with feelings of anger and disbelief. There was no way anyone was going to tell me that my daughter would be delayed simply because she was blind.

I understood that correlation does not imply causality. I believed that being blind could be related to the occurrence of developmental delays but I did not believe that those delays were caused by blindness itself. Perhaps they were tied to low expectations or lack of opportunities. One of my first steps was to find therapists who shared my high expectations. If a professional believes your child cannot achieve something, he or she is the wrong person for the job.

If one believes that being blind does not in itself cause delays in walking, then what other factors may be responsible? It is possible that a child who is blind might lack the motivation to move out into space because she can't see that there are interesting things to explore. Perhaps the child fears the unknown and does not wish to move away from a place she considers safe and familiar. Kendra did prove her therapists wrong and walked at fifteen months. We bought her Pip Squeaker shoes that squeaked with the weight of her feet. The sound helped motivate Kendra to place her feet on the ground. At eighteen months, she got her first cane which extended the boundaries of her world and gave her feedback about the world around her.

When my son, R.J., was born three and a half years after Kendra, I truly realized how much a baby learns visually by observing others. For instance, I never had to teach my son to eat with utensils. He learned by watching others and imitating what he saw them do. Kendra, on the other hand, needed to be taught how to use a spoon and fork. We used hand over hand techniques to guide Kendra through scooping motions associated with utensil use. We gave her opportunities to practice scooping sand, rice and beans. Another trick was to put small, medium and large bowls of oatmeal in front of her and pretend she was Goldilocks. Kendra learned to use a spoon in non-visual ways. Does that mean that being blind somehow made her unable to eat with silverware? Does it make sense to say that simply being blind prevents a child from walking until the age of three. I don't believe it does. A child who is blind simply may need alternative methods to learn a skill. While I may have provided few answers in this piece, I hope I have raised some important questions. With careful thought and research, perhaps we can sweep aside the notion that, in the case of children who are blind, correlation implies causality.

(Kendra is an adorable Lekotek alumni.)

Fundraising Events Raise Funds & Fun

In order to meet its annual budget, Lekotek depends upon foundation, corporate and individual support in addition to special events. For more than a decade, three annual special events have included a golf tournament, run and silent auction. This year's golf tournament held in May at Smoke Rise Golf and Country Club raised \$15,000. The 18th annual Lekotek Run raised \$50,000 with a record number of participants. Mark your calendars now for the annual silent auction to be held November 7th, 8th and 9th, at the Athletic Club NE in Executive Park.

We appreciate the generous support of, Festivity, a clothing and gift shop, that implemented Shop for a Cause and chose Lekotek. In May, a percentage of revenues for one day raised \$1,060. The next Festivity Shop for Lekotek day will be Thursday, December 2nd from 5:30 to 8:30.

We're happy to inform our readers that more than 90% of all donations are allocated to direct services for children and families. If you would like to volunteer and/or donate to any of these events, please call the Lekotek office.

The Five Ws of Special Needs Trusts

by Chris Miller, Esquire

What are Special Needs Trusts? All trusts are like baskets. Baskets hold and carry things from one place to another. Trusts hold money and help it pass from one person to the next. When a parent leaves assets behind for minor children, the children do not have the skills to manage them properly. Funds are held in a trust so we are confident they are allocated to education, health and support. The trust's language tells the Trustee when to make distributions of property and delineates the goals for the funds. Special

Needs Trusts are similar to regular trusts. They hold property for beneficiaries who are not ready to handle property on their own. What sets them apart is that they provide for the long term benefit of the beneficiary with special needs. Rather than distribute funds when a beneficiary graduates from school or reaches a certain age, a Special Needs Trust holds assets throughout the beneficiary's lifetime. It also carefully distributes the funds with the goal of preserving the beneficiary's eligibility for state and federal assistance.

Who manages the Trust? It is important to carefully choose who will serve as Trustee. The Trustee should be familiar enough with the beneficiary to know when a distribution is needed, even if the beneficiary does not know or cannot ask. Trustees should have the ability to decide how much to withdraw for current needs without compromising the trust's ability to make distributions over a lifetime. A Special Needs Trust is likely to last a long time, so it is good to appoint a line-up of Trustees three or four deep. Some trust companies will appoint a Trustee if a family member or friend cannot be selected.

When do I need one? A Special Needs Trust should be drafted whenever a family member wants to leave a beneficiary money to help care for their needs. One common pitfall is that grandparents will leave a share of their estate to all their grandchildren with the unintended consequence of disqualifying the grandchild with special needs. A Special Needs Trust can solve that problem.

Why is the Trust so important? Children with special needs are likely to be eligible for government assistance. A Special Needs Trust does not "hide" assets. It restricts the distributions to benefits outside the scope of services typically provided through government benefits. In this way, the government pays for basic support and the Trust can be used for specialized services.

Where can I get one? – Special Needs Trusts require knowledge in this field. Don't be shy in asking whether your attorney has experience in drafting Special Needs Trusts. There are attorneys who specialize in this area.

Family Profile: Meet the Allis

When Bryan and I relocated to Bangalore, India in May 2006 on a short-term work assignment little did we know we would return to Atlanta two years later with a child.... furthermore, a child with special needs. We were a recently married, happy go lucky couple, whose greatest daily concern dramatically shifted from what to do for dinner to how do we schedule orientation & mobility, occupational therapy and vision services for our daughter.



Born with bilateral anophthalmia (the absence of both eyes), Raveena entered our lives when she was 10 months old while I was volunteering at an orphanage in India. Subsequently our foster and adoption journey began....

Raveena spent the first 10 months of her life lying in a crib on her back with no sensory or audio stimulation. Realizing and understanding that she needed more care than was available at the orphanage, Bryan and I were approached about fostering Raveena for 4 months or until the orphanage was able to identify an adoptive family. Our goal was to provide a loving and stable home environment while meeting her medical needs. As time passed, Raveena grew stronger and so did our bond as a family.

When we returned to Atlanta with Raveena she was 2 and half years old and would cruise holding onto furniture but was not walking independently and had no structured language skills. She was hesitant to interact with the world around her. Upon our return we learned about resources such as Babies Can't Wait, the BEGIN program at the Center for Visually Impaired and Lekotek. Raveena is progressing remarkably well, developing at the same level as her four year-old peers. Raveena walks independently with her cane, can identify shapes and recently started to learn braille.

Lekotek has been a wonderful resource. Raveena looks forward to her one on one play time with Lekotek leader, Jennifer, who focuses on developing her speech, cognitive and fine motor skills. She enjoyed Compuplay (computer) sessions with Kristen last fall and recently had the opportunity to attend her first camp at Lekotek - which she LOVED!

Raising a child with a visual impairment has been a journey that has taught us many lessons and we look forward to the many more to come. We know Raveena was meant to be our daughter and there was a greater purpose to being in India beyond a work assignment. People say Raveena is lucky to have us, but Bryan and I feel blessed that our paths crossed and she entered our lives.

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Lekotalk

Lekotek of Georgia
Making a Difference for Children with Disabilities

This Year, For the First Time, Lekotek Families Attended an Emory Baseball Game

Lekotek’s mission is the inclusion of children with disabilities into their families, schools and communities. While the heart and soul of Lekotek is the family play session in which adapted toys, educational software and adapted computer devices are used and loaned to families, Lekotek works closely with schools and community groups to promote inclusion. For the first time, Lekotek families attended an Emory baseball game. The game ended in the ninth inning with an exciting 6-5 win for Emory. A good time was had by all and we look forward to a continued partnership with Emory Baseball.



UPCOMING EVENTS

- October Compuplay
- November Club
- November Leko Pals
- November 7th, 8th, 9th - Silent Auction
- December 11th– Annual Holiday Party

Please visit our website for a full calendar of events.

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