

# PATH in *Print*

**AN INFORMATION AND SUPPORT RESOURCE FOR FAMILIES OF CHILDREN WITH  
SPECIAL HEALTH CARE NEEDS**

## **Hidden Disability**

**By Nanfi Lubogo**

What is a hidden disability? I like the definition that I found online on the Open University Website: “Hidden disability’ is a catch-all phrase that simply means that a person’s impairment or condition is not obviously apparent or visible”. Hidden disabilities can include some people with visual impairments and those with dexterity difficulties such as repetitive strain injury. It may also include those who are hard of hearing or have mental health difficulties. However, it is probably more commonly used in relation to people who have disabling medical conditions of one sort or another.

The list of medical conditions that may be regarded as hidden disabilities is very long and the effects of these different conditions are many and varied. It can include people with epilepsy, diabetes, sickle cell condition, chronic fatigue syndrome or ME, cystic fibrosis, cancer, HIV and AIDS, and heart, liver or kidney problems.

You may hear the parent of a child whose disability is not readily evident express frustration say that sometimes they wished their child was in a wheelchair so that they did not have explain what the issue was, it would be visible. Your first inclination may be to pass judgment on how horrible the thought is but the reality is that that is the misconception that most people have. Society tends to think that people in wheelchairs are “handicapped” and incapable of much, or that you can’t have a disability if you are not wheelchair bound. The truth is that disability is so vast and varied that you will find individuals with disabilities’ that look “normal” on the outside, yet they live with complicated conditions like mental illness, cystic fibrosis, severe learning disabilities etc. All of these medical issues can be extremely difficult to live with and often affect many aspects of the individual’s daily life. All people who have disabilities deal with the stigma of

society even though society tends to be kinder or more tolerant to those in wheelchairs because of the visual reminder.

One mother of a child with sickle cell disease expressed the frustrations she faced many times when her child ended up in the Emergency Room. Individuals with sickle cell disease suffer from extreme chronic pain in the chest, back, hands or feet. Outwardly they look and sound “normal” even when they are in extreme pain. This family found that they had to visit the emergency room quite a bit between doctor’s appointments and during some of these visits they were sensed skepticism in their sincerity for being there. One care provider even asked them if the child really needed medication because according to them the child did not look sick, despite all their efforts to describe what they were feeling. There was the insinuation that they were overreacting. Fortunately this mother was a good advocate for her child and was able to speak up and show them that she understood what the symptoms of sickle cell were and what would help to get her son comfortable. Another time, it was there was the insinuation of drug abuse. This mom, frustrated with having to explain that they did indeed understand the disease, took matters into her own hands. She now carries around a file all about her son and his medical condition that includes reports from his physician. It is really sad that this is what it takes for some to believe her.

I could totally relate to her situation because my daughter has a high tolerance for pain that is part of her syndrome - Parder Willi. We have made many trips to the emergency room for different issues and even when she is very sick her disposition rarely changes and she’s always smiley and polite. Because of that we have heard comments on how she does not look sick or in pain. Sometimes there is that insinuation of overreaction. I always have to mention that she has a high tolerance for pain and therefore we have learned to look for other clues that will let us know that she is sick. I notice that the reaction is very different once they see her much scarred back or see x-rays that show how much hardware she has in her body.

Fortunately like my friend, I am also able to advocate for our needs but I often wonder about those that don’t speak English or those that have a limited understanding of their child’s condition. How do they explain to people that no, my child is not having a tantrum and banging his head against the wall because he is a bad kid, he is doing it because he has a disability, and it may not be obvious by just looking at him. I am not a bad parent and I really need your help and

understanding, if only you will just treat me the way you would any other person and just listen to me.

Please note I am in not saying everyone in society is bad, most people just don't get it because they know no better. Neither I am saying that all medical professionals/facilities are insensitive or clueless as mentioned above, in fact in Connecticut we are very fortunate that many of our medical facilities are family centered and practice the medical home model of "delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care. The same can be said on the education side, many districts welcome a partnership with parents and most concerns are addressed through the PPT process. It is not perfect, obviously there is still a lot of work to be done and some "get it" better than others. Some reading this will agree with me while others who have been burned will be skeptical. The bottom line is that the responsibility ultimately falls upon us as parents and as leaders of parent support organizations. We must educate ourselves, learn how to advocate and teach other parents.

In closing I'll say, dealing with a hidden disability is no different than dealing with any other disability or medical condition. I think that is where the term "special needs" must have come from. We are all in it together (can't ever say that without thinking about High School Musical.. so hum it with me), our children might have special needs but we still think of them as we do our other kids..special. We just want everyone else to do the same.

***Some useful advocacy tips***

- ***Use a binder to keep important info on your child with special needs. PATH/FVCT suggests DPH's Directions Resource Binder. Call 1-800-399-7284 to get one. Eng. Spanish, Portuguese.***
- ***Type out useful info and transfer onto a portable thumb drive. Take to appointments, ask Docs to email reports.***
- ***Regularly update info.***
- ***Plan for emergencies, have an emergency plan in place, include your child with special needs. Keep a ready to go bag filled with important info such as picture of child, disability, DOB, list of medicines.etc.***
- ***Network with other parents***
- ***Educate yourself, your family and others about your child's special need.***

# *You've Come a Long Way **Baby!***

By Carolyn Lynch

This August, my son Kevin will be eight years old. My husband and I often ask ourselves if his birth feels like yesterday or if it feels like we should be taking him to college! Kevin's birth was a little more eventful than anticipated.

Our second son, Kevin came into this world with a relatively easy delivery. At first glance, he was a beautiful, healthy baby boy who looked an awful lot like his older brother. Within moments of holding him, though, it became very apparent that something was wrong. Kevin's color turned ashen and he was obviously not breathing. I immediately handed him to the nurse who literally ran him to the NICU. What seemed like hours later, really only minutes, the Neonatologist came in to speak to my husband and me.

We were told that Kevin had a significant cleft of the soft palate that had resulted from an underdeveloped chin. Basically, his chin was so recessed that his tongue had nowhere to go but up. Thus, his palate was unable to close as it should have. The bigger issue was that his tongue was blocking his already small airway and preventing him from breathing on his own. I will never forget the Neonatologist's answer when I asked if Kevin would ever be able to breathe on his own. He looked directly at me and said "I don't know". My heart sank lower than I ever believed possible. I immediately went to the NICU to be with Kevin. I just held him and kissed him and promised him I would make everything ok. I knew in my heart that he was a fighter, but he looked so fragile with his oral airway taped over his mouth and the numbers of tubes monitoring his breathing and oxygen levels. Despite all of that and the activity of a NICE, Kevin and I bonded in moments. He was so perfect in my eyes.

The ambulance came to transfer Kevin to a hospital with pediatric surgery capability. I was discharged and followed with my husband. In that time, my husband and I found a strength that can only be born of desperation and determination for the well-being of your child. We were silent except to reassure ourselves that we both knew this kid was tough. Thankfully, it was quickly

determined that Kevin would not need surgery to correct his breathing issues. It was believed that his chin would grow significantly within months and correct his breathing. His cleft would be repaired at a year. It was basically a watch and grow situation complicated with lots of positioning and feeding issues. We were able to take him home just before four weeks. He was on an apnea monitor to alert us of any obstruction to his breathing. He was not able to lie on his back, sit in a car seat, a bouncy seat or any other position of incline without struggling to breathe. He was best positioned on his stomach, which is how he slept. Kevin was fed by Nasal Gastric tube for two months and then transitioned to a bottle when he developed ulcers from his tube. Against the advice of many, we were confident that Kevin could thrive without his NG tube. We tried no less than twenty different types of bottles before finding the one that best helped him breathe and eat at the same time.

He quickly took to one kind and his feedings went from an hour to twenty minutes. Time so needed with a twenty month old at home!

Kevin began to thrive. As predicted, his breathing got better as he grew. I remember calling my husband one day in tears because I had put Kevin in his bouncy seat and he wasn't struggling to breathe. In fact, he smiled at me and hung his leg over the side like he was just hangin' out! Another big day was the first time we were able to put him in his car seat (he'd been in a car bed until then). He was looking around with his big wide eyes and was totally entertained. It was all I could do to watch the road and not stare in the baby mirror at his happy, upright face.

It is these seemingly ordinary moments that make you realize nothing should be taken for granted. These were huge achievements for Kevin.

Kevin had his cleft closed at a year of age. The surgery went beautifully and, true to form, he was a trooper. I am always amazed at what Kevin is able to adapt to. He was up and around and chasing his brother just three days after surgery. He has not slowed down since!! As I watched him eat pizza and shove cake into his mouth for his first birthday, I realized just how far he'd come in a year. Just twelve months earlier we were tube feeding him as he lay on his tummy. Wow, what a difference a year makes.

Kevin is a thriving first grader now and I have started volunteering in a local NICU. I look at these beautiful babies and their worried parents, and find myself

pondering how far we've come. On one hand it seems like yesterday, and on the other, a lifetime away. It seems impossible that this child who never stops moving was once unable to breathe on his own unless he was face down. Kevin is a child who should not be underestimated. From the day he was born, he defied all expectations. When he was said to need an oral airway for two months, it was out in a week. When he was said to need an NG tube for a year, it was out two months. When it was said he would be physically delayed due to his positional issues, he walked at ten months. Kevin achieves whatever he sets his mind to and does so with just enough drama to age his parents before his eyes! You won't find me complaining - he is everything I dreamed of that first hour in the NICU - a wonderful, happy, healthy, opinionated boy who finds humor almost anywhere. How far we've come!

# ***PATH on the Move***

## **PATH merges with CT FAMILY VOICES**

As you may have heard, PATH has gone through an exciting transition in the past few months. We have merged with CT Family Voices and our new name is now PATH/Family Voices of CT (PATH/FVCT). Earlier this year, the PATH Parent to Parent Board of Directors voted to merge the organization with Family Voices of CT and pursue status as the Connecticut State Affiliate Organization of Family Voices National. Family Voices is a national network of parents who have children with special health care needs, which was founded in 1992. The organization pursues national legislation, including funding for the Family to Family Health information centers now located in every state. They partner with national and state agencies, providers and families to better the lives of children with disabilities and their families. The State Affiliate status is part of a plan by national Family Voices to move to a membership organization, with statewide parent run non-profit state affiliates in each state, individual members in each state, and organizational members in each state, all with accompanying membership dues and benefits.

This stronger Family Voices organization will increase the presence and effectiveness of the parent movement across the country in meeting the needs of Children and Youth with Special Health Care Needs. Both PATH and Family Voices of CT believe that this exciting merger will strengthen the family movement in Connecticut by mobilizing resources at the state and national level. As the State Affiliate Organization of Family Voices, PATH/FVCT will be able to access training and technical assistance in organizational development, non-profit management, and an array of informational and training supports to enhance their ability to support families in Connecticut.

**The FV Leadership Summit** held its first meeting in October, 2008. 19 parent organizations came together to discuss common needs, strengths and collaboration. They determined that quarterly meetings of leaders of family organizations would be productive and agreed to another meeting in February, 2009.

**A directory listing all of the parent organizations is available through PATH/Family Voices of CT.**

**The FV Leadership Summit** met again in February, 2009. At that meeting, the group decided that one common theme was the need for improving the experience of families who access Emergency Services. It was decided that this would be a good event for the Leadership Summit to host.

**PATH/Family Voices of Connecticut** sought additional funding from the CT Department of Public Health, and received the financial support to convene this conference. **The FV Leadership Summit** convened again in May, 2009, and a small planning committee has met through the summer to implement the EMSC conference.

***The Family Voices Leadership Summit***

***will meet again on February 10th from 12:30-3:00 in Farmington, with lunch provided. Parent leaders of parent organizations are welcome to attend.***

***Please contact Cathy Adamczyk at 860-679-1585 or Adamczyk@uchc.edu***

***if you would like to attend.***


## **TRANSITION GRANT**

Since 2008, PATH/FVCT has been fortunate to be part of a Transition grant which focuses on strengthening efforts on continuous quality improvement to promote the successful transition of youth with Special Health Care Needs to post-secondary education and/or employment or vocational placement and from pediatric practices to adult health care services. This grant is a collaborative effort between several state and family organizations in CT and is funded by the CT Department of Public Health (DPH).

PATH/FVCT would like to invite families who have youth with special health care needs who are in middle or high school who would like to learn more about transition to visit our website [www.pathct.org](http://www.pathct.org) On the website parents can complete a simple survey to determine the transition needs of their youth and youth can complete a transition checklist that has questions that address key transition issues that include insurance, independent living skills, community involvement and youth decision making. PATH/FVCT staff can also assist families to access transition resources.

Please watch that space for upcoming workshops and information about transition.

# SAVE THE DATE...

<h1>THE <sup>★</sup> AMAZING New Show 70's PROM <sup>★</sup></h1>	
<p>Step into a world of laughter and fun in this hilarious interactive comedy prom. Volunteer to be part of the show or sit back and watch the antics as the faculty vainly attempts to stop this wild prom from spinning out of control.</p> <p><b>Dancing, Audience Participation, Fun</b></p>	
<p><b>Annual Gala Dinner,</b></p> <p><b>Silent &amp; Live Auction &amp; Dinner</b></p> <p><b>March 13, 2010 6:00-11:00pm \$85 per person</b></p>	
 <p>PATH Parent-to-Parent Family Voices of Connecticut</p>	<p>Where: Fantasia 404 Washington Avenue North Haven, CT</p> <p>For more information: 203-234-9554 Or 1-800-399-7284</p>

# PATH Youth



## Stigma: The Theory of Defining One Self

By Emily Ball 17 years old

Stigma, what is it? Besides a funny structure of letters that seem out of place when grouped together, it can also define who you are. Social stigmas can be categorized in three basic ways: mental illness, physical disabilities, and racial or ethnic discrimination.

A prime example of a stigma is how “regular” people react to a person with Down’s syndrome: People with Down’s syndrome are like any other people; they just have a different mental capacity. Unfortunately, many in society discriminate against people with Down’s syndrome.

This is just one example of the stigma of disability discrimination, and I can personally relate my similar experiences. You see, unlike a person with Down’s Syndrome, I have a physical disability: I was born prematurely which led to my cerebral palsy. When you’ve got a physical disability like mine, you are prone to ridicule and the feeling of being different. I can remember that when I was little (before I started school) I didn’t know I was different. That all changed when I started kindergarten. The reason for that is because kindergarten is when I got my first wheelchair.

All throughout my school years, I knew I was different. In elementary school, this became apparent at recess time when all my classmates were able to run around

and play on the playground. Of course I had friends that hung out with me, but they never really hung out for the whole fifteen to thirty minutes we were outside. I was always by myself.

In middle school, that feeling of being different reappeared in the form of school dances. Instead of sitting on the sidelines wishing I could play on the playground like a “regular” kid, I was sitting on the sidelines watching other kids dance and wishing I could do the same. I remember being parked against the wall only to be subjected to masses of kids dancing to really fast music and wishing I could do that. I vividly remember just sitting there; eating the plate of snacks I was given. I don’t remember one instance where I moved my body. It was elementary school all over again.

Through elementary and middle school, I always felt like an outsider. When I hit high school, things changed, but not dramatically. In high school, I still feel that way but generally, everyone is more accepting. Although I’m accepted by peers and everyone at school and some other places I go, my disability and therefore myself, are not accepted by the unknowing public. For example, when I’m out with my parents, I often get gawked at. This doesn’t faze me; I don’t even realize it sometimes. The only thing that bugs me is when people come up to us and ask my parents: “Does she talk?” When this happens, I *want* to talk, but I just can’t seem to get out the words.

I fully understand where these people are coming from, and though thanks to my parents’ never-stopping complaints about when people do such things, I kind of agree with the people, but I disagree too. On certain occasions when I hear a little kid ask their mom, “Why is she in a wheelchair?” the mom responds, “Because she can’t walk,” I don’t find that any less weird than I find the stares.

Though my situation is different than racism, I feel there are similarities. While people that are of African - American, Hispanic, and Asian descent are often excluded from the Caucasian world, disabled people are often excluded from the “normal world.” For example, the store in the mall, Hollister, makes cool clothes but I’m unable to wear them because there are stairs leading up to the entrance of their stores.

The stigmas experienced by mentally challenged, racial or ethnic minorities and the physically disabled have defined these groups for years. Although the discrimination may be different for each group, they are all being shunned by their specific opposites. The physically disabled being shunned by the able-bodied, and the Black man being shunned by the white man are just two specific examples. In my own case, I have learned not to let others' problems get in the way of living my life.