



# Complex Child E-Magazine

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## Improving Attitudes of Medical Professionals Toward Children with Neurological Impairments

by Susan Agrawal

*Noah was called a “twit” six times during one appointment with a developmental pediatrician.*

*Molly’s parents were asked if they wanted to forego treatment for an illness simply because she was neurologically impaired and perhaps not “worth it.”*

*Jaden’s mom, when making treatment decisions about her child with a metabolic disease, was told by his pediatrician, “It’s not like you can go to Big Lots and buy him a new brain.”*

Unless you are exceptionally fortunate, as a parent of a child with a neurological impairment, you have most likely experienced a nurse snickering about your child, a doctor uninterested in caring for your child, or a resident complaining about how your child is too much work. While not always the case, in many medical centers around the country, children with neurological issues do not always receive adequate care due to the prejudices of medical professionals.

### **The Rationale Behind Insensitivity**

Like most cases of insensitivity, bias against children with neurological impairments usually stems from ignorance. Most doctors and nurses have never parented a child with special needs and do not know how rewarding it can be. Similarly, the nature of our medical system is to always construct a barrier between the doctor and the patient, meaning that it is rare for a medical professional to truly get to know your child on a personal level.

The most common reason some medical professionals do not treat our children appropriately is because they simply do not know what to do or where to start. They lack both experience and training, which means they neither feel comfortable nor competent when it comes to caring for children with special needs. Many have had little training in treating children with physical disabilities or cognitive impairments, and a large percentage do not see members of this population frequently.

For some physicians, even some of the most caring and compassionate, working with children with special needs can be incredibly frustrating. In this era of managed care, greedy insurance companies, and cash-starved Medicaid programs, most doctors simply are not permitted the time or money to adequately care for children with special needs. They are not compensated for care coordination, writing letters of medical necessity, and other daily tasks required for children with chronic conditions. They also struggle with a paucity of resources in the community, such as a shortage of aid to address complex social situations or the inability to provide therapies and equipment. Many doctors are completely overwhelmed by the medical and adaptive needs of children with neurological impairments. Our current medical system is simply not designed to help children with chronic conditions thrive, and this clearly affects many doctors.

Some medical professionals also feel powerless to help children with neurological issues when so little is understood or can be done about their conditions. Many doctors still operate under the assumption that they are healers, and as a result have difficulty handling situations when healing is not an option. Like many individuals who have not had experience with kids with disabilities, some medical professionals also have profound emotional reactions to our children, which may cause them to remain aloof or be unwilling to treat children like ours.

Other more shocking reasons also exist, though these have fortunately become more rare. Some medical professionals see things in dollars and cents, and do not think money should be invested in the care of children who may never become independent members of society. Other individuals simply do not view children with neurological impairments as fully human, a group that is fortunately becoming smaller and smaller as time goes on.

Whatever the reasons may be, the halls of our children's hospitals continue to be filled with medical professionals lacking in sensitivity toward our children and their needs. And that is something that must change. It is never easy to change attitudes and traditions, but my hope is that with increased training and a commitment to addressing this issue, children with neurological issues will be treated with the dignity they deserve.

### **A PROBLEM: How Doctors Are Trained**

Unfortunately, most doctors simply are not trained to take care of children with neurological impairments and other complex medical issues. While this is not the only reason why medical professionals may treat children with neurological impairments with insensitivity, it is one that can be addressed more readily than others.

The majority of medical students will receive little more than a one-day lecture on conditions like cerebral palsy, autism, and cognitive impairment. They may encounter children or adults with these conditions during their clinical rotations, but the sole goal is to learn to treat their acute medical problems, and not to care for them as whole people. Medical students then graduate to become pediatric residents, who provide much of the basic care within children's hospitals as they perfect their craft. While all residency

programs require some experiences for residents in the areas of behavior, development, and child advocacy, the actual programs vary widely. Many institutions focus primarily on normal development or common behavioral issues, with little information given about children with complex developmental issues.

Studies on training of residents provide shocking insights into their lack of experience in chronic care. For example, a survey sent out to a selection of residents and practicing pediatricians revealed a striking lack of training for physicians in treating children with physical disabilities or neurological impairments.<sup>1</sup> Over 80% of physicians had absolutely no training on durable medical equipment such as wheelchairs or communication devices, and no more than five percent had greater than one hour training in this area. Almost all physicians, typically 90% or greater, rated their training as inadequate.

Physicians also received little training about common therapies, such as physical, occupational, and speech therapies. 66% to 75% of practicing physicians received no training in each of these therapies. Residents rated their training slightly better, but 41% to 43% received no training at all. Of those who did receive training, less than one in five of all physicians had more than one hour of training. Most viewed their training as inadequate.

The same survey also questioned doctors about their training in specific disabilities, such as muscular dystrophy, cerebral palsy, spasticity, and bowel/bladder problems. 21% of physicians had no training in cerebral palsy, 24% had no training in muscular dystrophy, and 35% had no training in either bowel/bladder disease or spasticity. Of those who did receive training, only one in three had more than one hour of training in most categories.

The conclusion of this survey was that physicians, “may not be adequately prepared to provide the best care for the large numbers of children with special health care needs that may appear in their practices.”<sup>2</sup> This is a damning statement, and one whose importance cannot be underestimated. How can we expect physicians, who may have had no training in equipment, therapies, or the diseases our children face, to adequately treat our children? How can we expect them to even begin to understand the complexity of our children as individuals, as well as their medical complexity?

While few institutions require their residents to actually learn about children with special needs and even fewer require residents to participate in a rotation for chronic care, some medical centers are attempting to incorporate some training into their programs. The American Academy of Pediatrics Medical Home website lists seven model programs in this area, which can be viewed at <http://www.medicalhomeinfo.org/training/residency.html#Model>

Shockingly, some of these “model programs” consist of little more than three or four hours of training for residents. While better than nothing, this is by no means adequate.

With most residents receiving such a small amount of training in the care of children with neurological impairments, it is impossible for them to grasp the varied needs of this population. They have no mechanism to develop sensitivity toward our children or learn to view them as the wonderful human beings they are. This ignorance may come off as insensitivity, especially when the leadership in their hospital does not discourage such behavior.

### **A SOLUTION: A Model for Change**

One program, Project TEAM at Children's Hospital of Wisconsin, provides comprehensive resident training on children with special health care needs. Training is integrated into all three years of resident education, culminating in a rotation on children with special health care needs in the final year of training. Activities include learning about care coordination, durable medical equipment, seating and equipment, home nursing care, physical, speech, and occupational therapies; visiting with families; attending outpatient clinics for children with cerebral palsy, spina bifida, or similar conditions; visiting regional information centers; and even visiting school programs for children with complex medical issues. Residents also write about their experiences and complete a final project on a topic of their choice.

While this level of training certainly prepares residents to care for children with neurological problems, it also creates a culture of sensitivity toward these children and their families. Here are some reflections from past residents who have gone through this rotation:<sup>3</sup>

*Being a physician I tend to focus on the disabilities of the patients and forget to look at the capabilities. Sometimes it is hard to see the quality of life or what the future holds for them. This mom helped me understand that these parents still have hopes and dreams for their children to lead the best life that they can. Isn't that really the hope that all parents have for their children?*

*Functionality is really what parents care about and want to talk about. I think as a resident, that is one aspect of a child's care we overlook daily.*

*This was probably my best experience thus far to truly understand a family with special needs.*

*So often some of these children seem untouchable and fragile; as if you move them the wrong way and they'll break (especially when they are hospitalized). At PEC [care center for children with complex medical issues], these same kids are happy, running around and giving you attitude (like they should be at their age) it was refreshing.*

This program helps to create a culture of sensitivity that permeates through every aspect of care at this hospital. It is simply expected that each doctor, nurse, and member of the support staff be respectful and understanding toward children with special needs. The leadership at this hospital prioritizes the care of children with special needs, thereby creating an environment in which children with special needs are treated with the utmost respect and dignity. These children are valued, and, in fact, many are doted on and loved.

Training programs like these, and the accompanying paradigm shift they create within the entire environment of a hospital, are vital to the nearly one-third of children in the United States who have some type of chronic or special medical needs. This program has shown that it is possible to succeed in this area, and that both doctors *and* families are the beneficiaries.

### **Further Suggestions**

Training is definitely essential in changing attitudes toward children with neurological impairments. The following are additional suggestions to help make these changes.

- ❑ Neurological impairment does not necessarily mean cognitive impairment. Many children with the greatest motor issues are cognitively normal, or close to it. Do not make assumptions based on appearances. Instead, treat all children as if they can understand you and respond appropriately.
- ❑ Training must include visits with families and children in their natural environments (home, school, daycare), not just so doctors realize the magnitude of care required for each child, but to learn that these children are delightful and worthwhile. In addition, for attending physicians, it may be helpful to bring these children and their families into the hospital to discuss their lives during conferences or other medical lectures that are widely attended by hospital staff.
- ❑ Pediatricians need to provide comprehensive inpatient and outpatient care for children with special needs, including medical homes for all children, and care coordination for those who need it.
- ❑ Our healthcare system needs to be reformed, compensating physicians appropriately for the time needed to provide care coordination and comprehensive care for children with chronic medical conditions.
- ❑ Hospitals need to educate all staff through yearly or more frequent presentations about children with special needs, addressing them first as children and second as children with medical needs.
- ❑ All hospitals should have in place a strategy for dealing with physicians, nurses, or other staff members who have a record of not treating children with neurological impairments or their families appropriately. This strategy should first emphasize education and sensitivity training, reserving censure only for repeat offenders.
- ❑ Most importantly, it should be an expectation that all children with neurological impairments are treated with respect and dignity at all times.

It is possible to change the attitudes of medical professionals--even those who have held biases for long periods of time--with just a little bit of education and sensitivity. My hope is that as more new doctors are trained to respect and understand the needs of children with neurological issues, the scandalous treatment of these children that occasionally still occurs will become a thing of the past. Just remember: not too long ago, children with epilepsy were institutionalized in insane asylums. We have come very far, and only have a little further to go.

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<sup>1</sup> Raphael C. Sneed, *et al.* "Training of Pediatricians in Care of Physical Disabilities in Children with Special Health Care Needs: Results of a T-State Survey of Practicing Pediatricians and National Resident Training Programs." *Pediatrics* 2000;105:554-61.

<sup>2</sup> Sneed, 560.

<sup>3</sup> Selected from, "What Residents Say About TEAM," and available from <http://www.medicalhomeinfo.org/training/residency/What%20Residents%20Say%20About%20TEAM.short%20doc.doc>