

Words and Numbers: A Parent's Perspective on Disability Research

AUTHOR: Elizabeth Bostic

Institute for Community Inclusion, Boston, Massachusetts

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Address correspondence to Elizabeth Bostic, Institute for Community Inclusion, 1295 Boylston St, Boston, MA 02114.

E-mail: elizabeth.bostic@verizon.net

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abstract

This piece is the commentary by Elizabeth Bostic, providing a parent view point on research and program development that affects children and youth with special health needs and chronic conditions. She points to the differences in culture between the general public and researchers and the need for the language we all speak to reflect common understanding. *Pediatrics* 2010;126:S143–S145

The organizers of the Opening Doors state-of-the-science conference asked Beth Bostic, the coordinator of family programs for Opening Doors, to offer her perspective on the research presented at the conference and in this supplement to Pediatrics. The following are her remarks.

I am the parent of 2 children with special needs. I have a 16-year-old drama queen who has attention-deficit/hyperactivity disorder and an anxiety disorder. I also have a son, James, who turned 9 years old in January 2010. James has cerebral palsy and is nonambulatory, nonverbal, fed through a gastric feeding tube, and very cute. He communicates very effectively, considering that he is nonverbal. He is the reason that I became involved in this work. My perspective is that of both a practitioner and a parent.

I have been asked to comment on the articles and discussions from the Opening Doors state-of-the-science conference that took place in Bethesda, Maryland, on November 10 and 11, 2008, that are now being presented in this supplement to *Pediatrics*. Central to the conference was a scientific presentation by Stephen Blumberg. He discussed the identification of disabilities, with a particular emphasis on culturally diverse populations and, in particular, the Latino population. His work¹ showed lower rates of parent-identified disability in the children of Spanish-speaking households than in non-Hispanic white households. At the time of his presentation in Bethesda, I watched a visceral emotional reaction go through the room as I heard him say the words, "There is no evidence of response bias in our research." I chuckled to myself because, although there does not seem to be any evidence of response bias in pediatric disability research, we all know that it occurs. That is part of the reason why so many parent

and community participants were drawn to this meeting—to try to determine what is really going on. Why are providers and programs unable to reach all of the families that need help effectively? Considering this apparent disconnect, I was struck by the importance and significance of words and of the numbers that are used in research.

How can we produce the right numbers that tell us what is happening to our children with disabilities—how they are identified, how they are served, and what their long-term outcomes are? When research produces data, do these data truly represent the realities of children with disabilities? How can we interpret these data properly so that we can determine the truth?

The Bethesda meeting exposed the current struggle. Dr Blumberg talked about his research findings that stemmed from an intellectual or cognitive point of view, and people understood that he had found lower levels of parent-reported "disability" among some groups, particularly Latinos, but we had trouble squaring this result with what we have experienced in the community. As I heard Dr Blumberg's explanation of the "lack of bias" in the methodology, I said to myself, "Therein lies the problem." Our language is not always interpreted in the same way by all people. If a person from a different cultural background reads what I am writing, how do we know that the way in which they are internalizing and processing my words actually aligns with what I intend to communicate? Language as we know it does not simply stop with a word's dictionary definition. There is so much more to language, such as cultural nuances, feelings, and the variety of contexts in which people internalize the data that they receive.

Researchers have a rather unenviable task. Researchers must follow stan-

dards and guidelines to ensure that they produce authentic data and evidence. But, how can we create the environment that is going to get us to where we want to go? Remember the Petri dish? Remember when we were in school and we grew things in Petri dishes to gather evidence of whatever we were experimenting with? If you are trying to grow bacteria and you spray Lysol over them, they will not grow; you will not achieve the desired effect.

During the meeting, many participants used the term "community based." What does "community based" really mean? Does it mean inviting people to come and participate in a study? Many people believe that "if you build it, they will come." However, we are finding that culturally diverse populations do not come to participate in our studies or, if they do come, they do not talk. How can we create an environment that will allow us to collect the information that we need? Furthermore, how can we do this while abiding by the standards that researchers need to follow to collect data and translate those data into the numbers we need to obtain funding?

In addition to the complex questions of how different populations respond to research questions, the conference brought out a fascinating tension related to how the able-bodied participants at the conference viewed disability. Some participants were awestruck by 2 young college students with disabilities who gave presentations. Other participants wondered, "Why is everyone so awestruck by these young women? They are simply representatives of the goal for all children with disabilities and special health care needs." It is true that these young women have achieved what we hope all young people with disabilities will achieve. However, different people view this issue from the perspectives of various worldviews and lenses.

Some people have never considered the possibility that a child with a disability might attend college.

I remember the day that I first met Keith Jones, the director of *Soul-Touchin' Experiences*, who also attended the Bethesda meeting. Keith is a wonderful inspiration. He has conquered his disability and is an example of what I have been picturing for my son. We have all experienced a moment at which we saw someone with a disability achieving something we had never imagined to be possible, and we were all awestruck at that moment. However, we must realize that this is the goal for which we have been struggling and fighting.

We need to determine how to interact with all of the families of children with disabilities that need help. How can we

learn what is valuable and useful for these families so that we can provide them with authentic and meaningful assistance? To do that, we must truly understand all of the families with which we interact.

In the meeting, participants discussed cultural partnerships and research that have helped researchers understand the backgrounds of participants in studies of children with disabilities. I hope that we completed some ground-work at the meeting related to the research challenges. During 1 recreation presentation, for example, participants discussed the limited number of measures available to help assess a child's physical status. How can we collect more data to measure children's progress? We will need creative solutions, many of which will come from meetings such as the state-of-the-

science conference, at which ideas are shared from many perspectives.

Finally, presenters at the meeting discussed a great deal of cutting-edge research. However, many participants said, "We have the data, but we are not acting on what we have," and this is absolutely true. How can we collect the right types of data and words to develop recommendations that are sustainable, feasible, and actionable? How can we use research results to make changes that we can actually see in the lives of children with disabilities? As we saw during the meeting, young adults with disabilities can go to college; 30 years ago, it was not possible in the United States. I challenge researchers in the field to find ways to shift from simply collecting information to translating the information we already have into action.

REFERENCE

1. Blumberg SJ, Read D, Avila RM, Bethell CD. Hispanic children with special health care needs from Spanish-language households. *Pediatrics*. 2010;126(6 suppl 3):S128S120–

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