

Medical diagnosis experiences and outcomes: Regional differences and similarities

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Overview

Our study examined mothers' memories of receiving a diagnosis of Down syndrome for their child, as well as outcomes measures for mother and child. Mothers answered a comprehensive survey which included demographic information, details about the mother/doctor interaction during diagnosis, nature of information provided at diagnosis, pre/post-natal care, and outcomes in the following years.

Because so many of the diagnosis experiences were highly negative, and because the negativity was related to doctor/patient interaction, we assessed whether there were any differences in these experiences across geographic regions in the United States. We compared reports from mothers in the Northeastern, Southern, Midwestern, and Western United States. We found many similarities in the diagnosis experience across geographic regions, despite well-known geographic differences in educational and support services across states. Unfortunately, the tendency for moms to experience flashbulb memories was high across regions, as was the likelihood of negative doctor-patient interaction. These findings suggest the need for changes in the way doctors are trained to provide a Down syndrome diagnosis, and affirm that there is need for change on a national level.



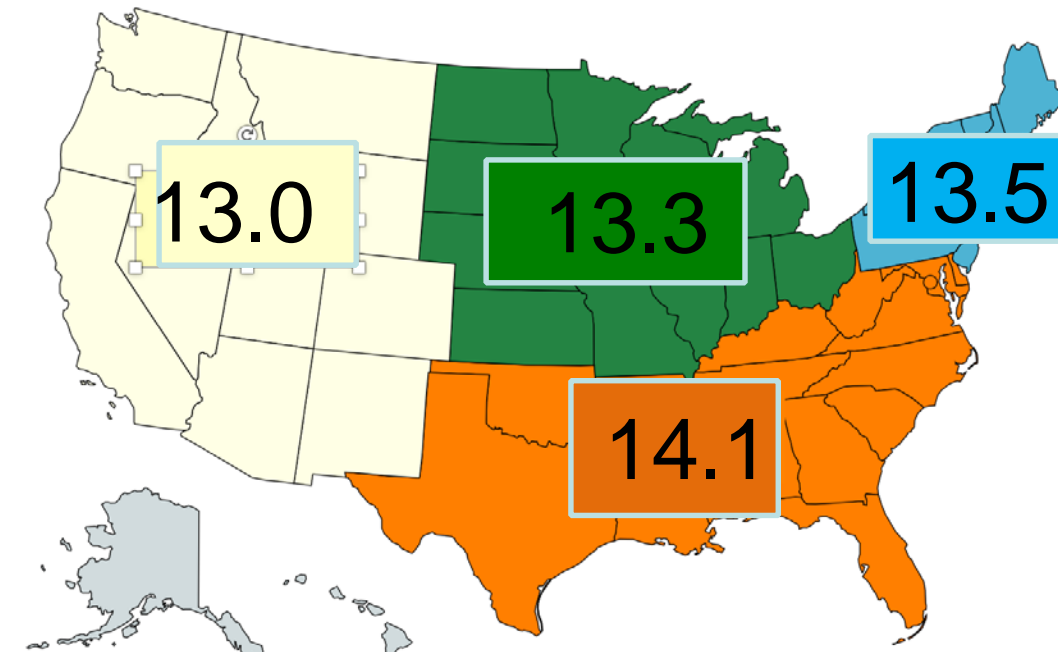
Participants

Participants included 281 mothers of children with Down syndrome who reported receiving medical care for their pregnancies in the United States. Of the participants, 70 were from the North East, 116 were from the South, 68 were from the Mid West, and 27 were from the West.

Method

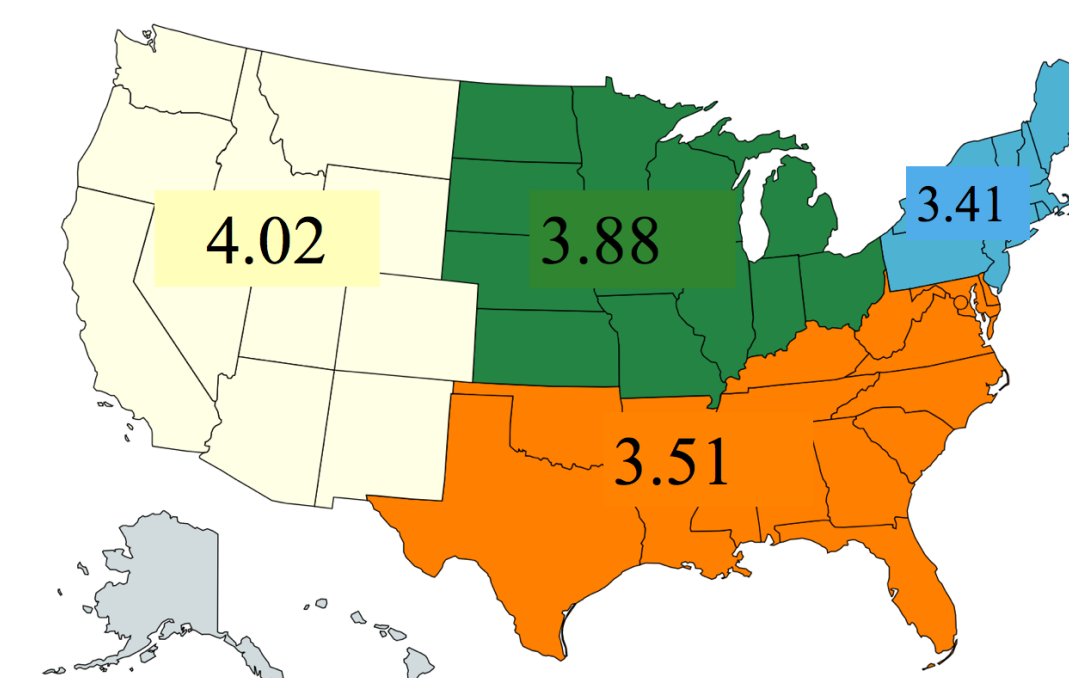
Mothers responded to an online survey containing questions about the diagnosis experience and outcomes measures. In this study, we assessed differences in the likelihood of forming a flashbulb memory and the patient/doctor interactions across geographic regions of the United States.

Average FBMC score by region (range 1 – 25)



* This pattern of strong FBMs across regions was replicated using TR scores.

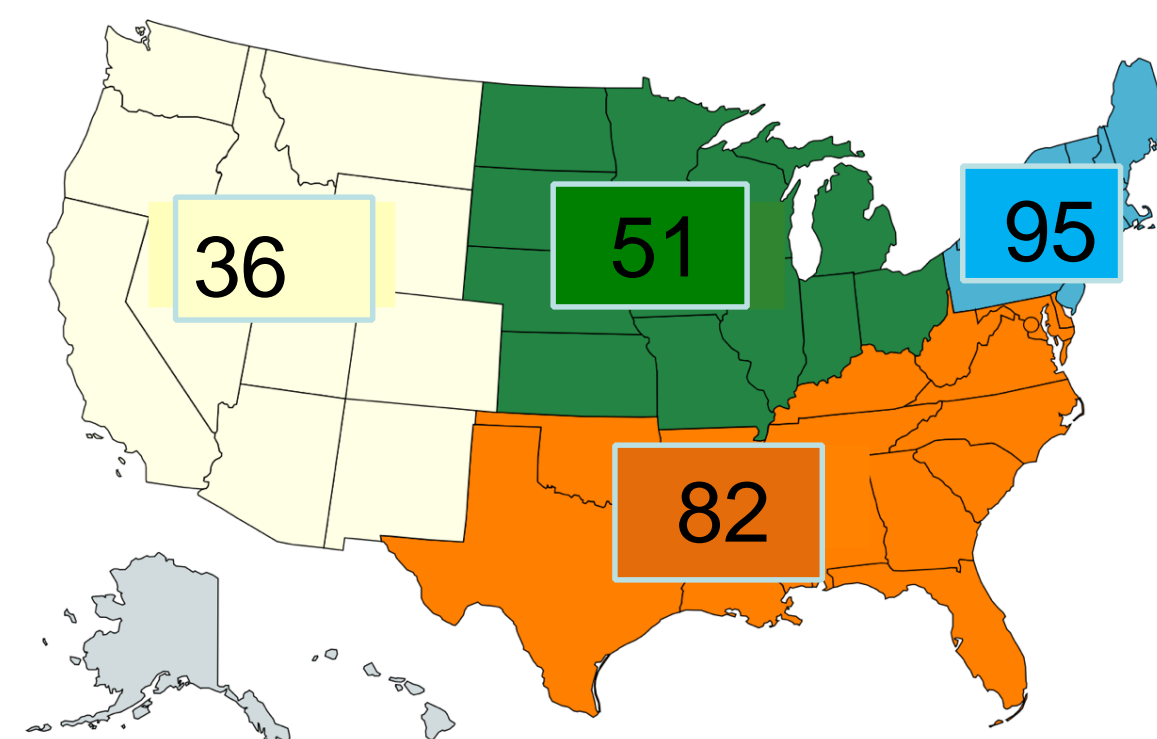
Mean response to: My doctor (or people in his/her office) emphasized the positive aspects of DS



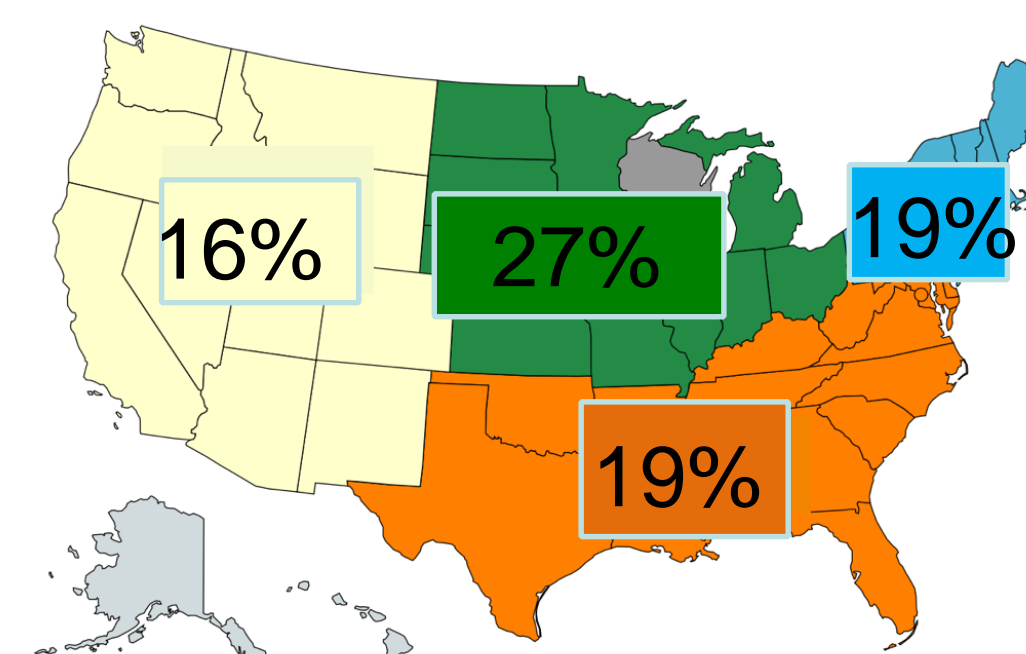
* Scale: 1 = Disagree; 7 = Agree. The pattern was similar for questions regarding the amount and nature of information about DS provided to patients by medical staff.

The similarity in scores across regions suggests that the **diagnosis experience is uniformly negative**. This contrasts with educational opportunities and health/therapeutic services, which vary by region (see examples below).

Number of colleges serving students with ID



IDEA Compliance Rates by Region

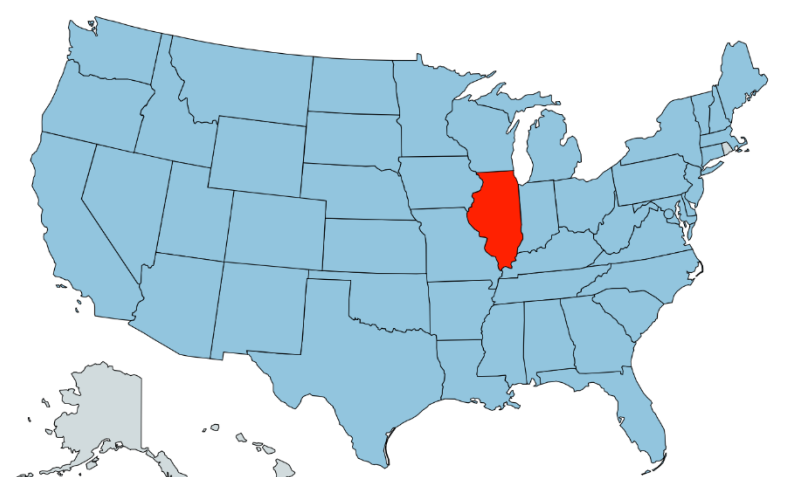


Samples of mothers' narratives about the diagnosis experience from across the country.

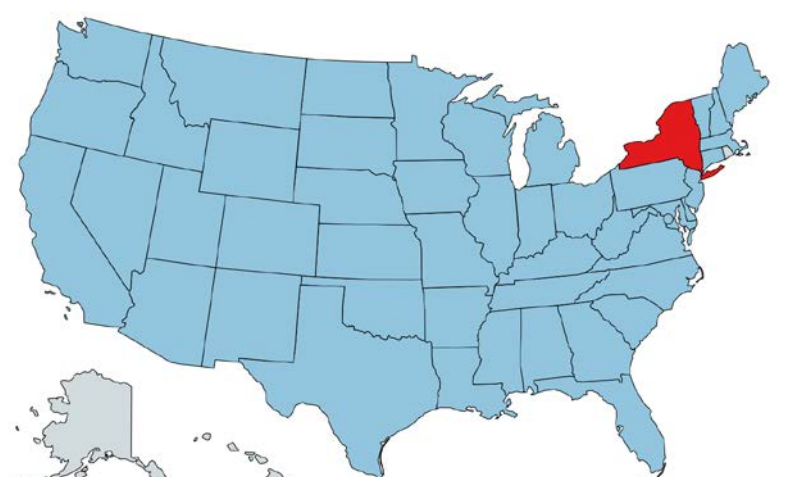
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 "I had no idea what [the doctor] was talking about, so I asked him if she was going to die? He laughed..... he laughed."  
 "They told us she won't be any smarter than a 5 year old and will die before 30 so you might as well put her in an institute."  
 - Florida



"I do remember as clear as day the last thing [the doctor] said... 'with a LOT of hard work, and a LOT of luck, these people can do things like greet at Wal-mart.'"  
 - Illinois



"Well, you know the baby has Down syndrome, right?' No. I didn't. I had always heard the expression 'all the air left the room'. I had never felt it until that moment. It left the room. It left my lungs." –New York



"My husband and I were in shock that a doctor, let alone one in a leadership position could be so ignorant. I'm so glad that we knew better. What if we hadn't??"  
 - California

